

LONG-TERM CARE: THE CRITICAL NEED

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

SEPTEMBER 15, 1989, PHILADELPHIA, PA

Comm. Pub. No. 101-748

Printed for the use of the Select Committee on Aging



U.S. GOVERNMENT PRINTING OFFICE

26-821

WASHINGTON : 1990

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

1141-8

SELECT COMMITTEE ON AGING

EDWARD R. ROYBAL, California, *Chairman*

THOMAS J. DOWNEY, New York
 JAMES J. FLORIO, New Jersey
 HAROLD E. FORD, Tennessee
 WILLIAM J. HUGHES, New Jersey
 MARILYN LLOYD, Tennessee
 MARY ROSE OAKAR, Ohio
 THOMAS A. LUKEN, Ohio
 BEVERLY B. BYRON, Maryland
 HENRY A. WAXMAN, California
 MIKE SYNAR, Oklahoma
 BUTLER DERRICK, South Carolina
 BRUCE F. VENTO, Minnesota
 BARNEY FRANK, Massachusetts
 TOM LANTOS, California
 RON WYDEN, Oregon
 GEO. W. CROCKETT, JR., Michigan
 IKE SKELTON, Missouri
 DENNIS M. HERTEL, Michigan
 ROBERT A. BORSKI, Pennsylvania
 BEN ERDREICH, Alabama
 NORMAN SISISKY, Virginia
 ROBERT E. WISE, JR., West Virginia
 BILL RICHARDSON, New Mexico
 HAROLD L. VOLKMER, Missouri
 BART GORDON, Tennessee
 THOMAS J. MANTON, New York
 RICHARD H. STALLINGS, Idaho
 JAMES McCLURE CLARKE, North Carolina
 JOSEPH P. KENNEDY II, Massachusetts
 LOUISE M. SLAUGHTER, New York
 JAMES H. BILBRAY, Nevada
 JIM JONTZ, Indiana
 JERRY F. COSTELLO, Illinois
 HARLEY O. STAGGERS, JR., West Virginia
 FRANK PALLONE, JR., New Jersey
 JOLENE UNSOELD, Washington
 PETER A. DeFAZIO, Oregon
 JOHN LEWIS, Georgia

MATTHEW J. RINALDO, New Jersey,
Ranking Minority Member
 JOHN PAUL HAMMERSCHMIDT, Arkansas
 RALPH REGULA, Ohio
 NORMAN D. SHUMWAY, California
 OLYMPIA J. SNOWE, Maine
 THOMAS J. TAUKE, Iowa
 JIM COURTER, New Jersey
 CLAUDINE SCHNEIDER, Rhode Island
 THOMAS J. RIDGE, Pennsylvania
 CHRISTOPHER H. SMITH, New Jersey
 SHERWOOD L. BOEHLERT, New York
 JIM SAXTON, New Jersey
 HELEN DELICH BENTLEY, Maryland
 JIM LIGHTFOOT, Iowa
 HARRIS W. FAWELL, Illinois
 JAN MEYERS, Kansas
 BEN BLAZ, Guam
 PAUL B. HENRY, Michigan
 BILL SCHUETTE, Michigan
 FLOYD SPENCE, South Carolina
 WILLIAM F. CLINGER, JR., Pennsylvania
 CONSTANCE A. MORELLA, Maryland
 PATRICIA F. SAIKI, Hawaii
 JOHN EDWARD PORTER, Illinois
 JOHN J. DUNCAN, JR., Tennessee
 CLIFF STEARNS, Florida
 CRAIG T. JAMES, Florida

MANUEL R. MIRANDA, Ph.D., *Staff Director*

PAUL SCHLEGEL, *Minority Staff Director*

SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE

EDWARD R. ROYBAL, California, *Chairman*

JAMES J. FLORIO, New Jersey
 HAROLD E. FORD, Tennessee
 MARY ROSE OAKAR, Ohio
 THOMAS A. LUKEN, Ohio
 HENRY A. WAXMAN, California
 MIKE SYNAR, Oklahoma
 BUTLER DERRICK, South Carolina
 BRUCE F. VENTO, Minnesota
 BARNEY FRANK, Massachusetts
 RON WYDEN, Oregon
 IKE SKELTON, Missouri
 DENNIS M. HERTEL, Michigan
 ROBERT A. BORSKI, Pennsylvania
 BEN ERDREICH, Alabama
 NORMAN SISISKY, Virginia
 ROBERT E. WISE, JR., West Virginia
 BILL RICHARDSON, New Mexico

RALPH REGULA, Ohio,
Ranking Minority Member
 MATTHEW J. RINALDO, New Jersey
 CLAUDINE SCHNEIDER, Rhode Island
 THOMAS J. RIDGE, Pennsylvania
 CHRISTOPHER H. SMITH, New Jersey
 SHERWOOD L. BOEHLERT, New York
 JIM SAXTON, New Jersey
 HELEN DELICH BENTLEY, Maryland
 JIM LIGHTFOOT, Iowa
 HARRIS W. FAWELL, Illinois
 PAUL B. HENRY, Michigan
 WILLIAM F. CLINGER, JR., Pennsylvania

KATHLEEN GARDNER CRAVEDI, *Staff Director*

MARK BENEDICT, J.D., *Minority Staff Director*

CONTENTS

MEMBERS OPENING STATEMENTS

Robert A. Borski.....	Page 1
-----------------------	-----------

CHRONOLOGICAL LIST OF WITNESSES

Mary Kay Pera, Executive Director, Pennsylvania Association of Home Health Agencies, and Co-Coordinator, Pennsylvania Long-Term Care Campaign.....	3
Tim and Diane Kaisenger of Philadelphia, PA, parents of Timmy Kaisenger....	16
William L. Keane, President, Greater Philadelphia Chapter of the Alzheimer's Disease and Related Disorders Association.....	17
Jerry Gibbons, West Chester, PA	23
Linda Hahn, Director, Older Adults Service of Family Service of Philadelphia.	30
Betty M. Stagg, Director, Product Development for the Aging, Independence Blue Cross.....	46
Frank Podietz, M.B.A., Director of Operations, Philadelphia Geriatric Center ..	68
Rodney D. Williams, Executive Director, Philadelphia Corporation on Aging....	87
Linda M. Rhodes, Secretary, Department of Aging, Commonwealth of Pennsylvania, prepared statement.....	103

APPENDIX

Additional material received for the record:	
Trudy Persky, Facilitator, Philadelphia Mental Health Aging Advocacy Committee, Philadelphia, PA, letter	113

LONG-TERM CARE: THE CRITICAL NEED

FRIDAY, SEPTEMBER 15, 1989

U.S. HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE,
Washington, DC

The subcommittee met, pursuant to notice, at 9:30 a.m., in the Auditorium, Juniata Older Adult Center, Hon. Robert A. Borski (acting chairman of the subcommittee) presiding.

Present. Representatives Borski and Manton

Staff Present. Mary McSorley and Peter DeCoursey, office of Representative Borski; and Melanie Modlin, Subcommittee on Health and Long-Term Care, Select Committee on Aging.

OPENING STATEMENT OF REPRESENTATIVE ROBERT A. BORSKI

Mr. BORSKI. Thank you very much. Ladies and gentlemen, let me open this hearing of the Subcommittee on Health and Long-Term Care, the Select Committee on Aging.

I want to first thank several people who helped to put this meeting together. First of all from the Juniata Older Adult Center, a big thank you to Lynn Spiro for all her help, for assisting and making this event happen. Lynn, thank you very much. I also want to issue up front, a special thank you to Melanie Modlin who is on the subcommittee staff. She has traveled up to Philadelphia to help us get under way. From my own staff, a thank you to Mary McSorley. Most of you out there know Mary who assists me on my personal staff and does an excellent job.

I also want to thank my colleague and good friend from New York for coming down to Philadelphia today to help in administering this hearing, Congressman Tom Manton. Tom, thank you.

As you all know our Nation lost a dear friend and a champion of the elderly a few months ago with the death of Claude Pepper. I had Senator Pepper up to Philadelphia on a few occasions for hearings as such as this, and I am sure he would have been with us this year if it were not for his death. I would ask at this point if we could just have a moment of silence in memory of Claude Pepper.

[A moment of silence was observed.]

Mr. BORSKI. Thank you very much. I am sure, however, ladies and gentlemen, that Congressman Claude Pepper is with us today in spirit. He is looking down at us as we have this hearing. By serving as a lasting conscience, he is helping, still, to make sure that this Nation of ours gets a full and comprehensive long-term care policy.

It is a tragedy that in a Nation as great as ours, families must bankrupt themselves to provide care for their loved ones. Of all the industrialized nations, the United States and South Africa are the only two which do not provide a comprehensive health insurance system to address their citizens' needs. There is currently no single Federal program which establishes services to assist families caring for chronically ill children and the elderly. Instead, families must "spend down" to poverty levels before the Medicaid program will cover the cost of nursing home or in-home care.

Last spring, I visited one family you will hear from today. They exemplify American family values through their commitment to each other and their ability to face the challenge of caring for their son in their home. Unfortunately, they have been forced to do it alone without a support network to assist them with the physical, emotional and financial burden of a long-term illness.

What is worse is that the witnesses who will testify today are only a few examples of many more families across our Nation who struggle day to day with the very same tragic problems. I believe that the late Senator Pepper had an excellent solution to this critical need.

I am a proud cosponsor of H.R. 2263, legislation which would provide long-term home care for chronically ill children and the elderly under the Medicare program. The plan would be funded by eliminating the \$48,000 cap on income subjected to the 1.45 percent Medicare tax. Under current law, employers and working people pay the tax only on the first \$48,000 in wages. This legislation would eliminate the cap and require contributions to Medicare on all income.

This may be a particularly good time for such a proposal. As many of you may have read this morning, the capital gains tax rate was cut so that the very wealthy people of our Nation are going to get another tax break. If you earn over \$200,000 a year, you are going to get a pretty good wage tax or income tax reduction on capital gains. This may be a good time then to try and lift that cap. This funding mechanism ensures that the plan would pay for itself while providing a critically needed benefit to all Americans.

I think we need to explore all avenues and all income sources to get this most needed program. I believe we must develop a sound policy for long-term care to alleviate some of the pressing burdens on our families, young and old. I hope you will join with me in the continued support for a sound Federal policy on long-term care.

Again, I want to thank my colleague, Congressman Manton, for joining me today. I also want to thank all of our witnesses who will share with us their experience and expertise. I look forward to hearing their testimony.

Our first panel will be, "Families and the Advocates," and we will hear from Ms. Mary Kay Pera, Co-coordinator of the Pennsylvania Long-Term Care Campaign and Executive Director of the Pennsylvania Association of Home Health Agencies, which represents many families needing long-term care.

Tim and Diane Kaisenger of Philadelphia are the parents of Timmy, a 9-year-old boy who suffers from a brain tumor and who

needs round-the-clock care. Mr. and Mrs. Kaisenger will describe their family's experience since the onset of Timmy's illness.

Mr. William Keane, President, Greater Philadelphia Chapter of the Alzheimer's disease and Related Disorders Association, representing families of Alzheimer's victims who cope with the burden and strain of providing long-term care in their own families.

Mr. Jerry Gibbons, husband of a 54-year-old Alzheimer's disease victim, will explain his struggle to care for his wife, Molly.

Ms. Pera?

PANEL ONE—CONSISTING OF MARY KAY PERA, EXECUTIVE DIRECTOR, PENNSYLVANIA ASSOCIATION OF HOME HEALTH AGENCIES, AND CO-COORDINATOR, PENNSYLVANIA LONG-TERM CARE CAMPAIGN; TIM AND DIANE KAISENGER OF PHILADELPHIA, PA, PARENTS OF TIMMY KAISENGER; WILLIAM L. KEANE, PRESIDENT, GREATER PHILADELPHIA CHAPTER OF THE ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION; AND JERRY GIBBONS, WEST CHESTER, PA

STATEMENT OF MARY KAY PERA

Ms. PERA. Good morning, Congressman Borski, Congressman Manton, my name is Mary Kay Pera. I am Executive Director of the Pennsylvania Association of Home Health Agencies. I am also Co-coordinator of the Pennsylvania Long-Term Care Campaign. On behalf of the families who currently need long-term care and those who will need it in the future, thank you. Thank you for your interest. Thank you for holding this hearing. We are honored to participate.

Congressman Borski, I ought to reiterate what you said. Our Nation faces a number of very pressing issues at the moment. We are here to consider just one. Millions are requiring long-term care and their numbers are swelling. The point I wish to make is really quite simple. I agree with you. We need a national, comprehensive long-term care program that covers home care and facility-based care, and we need it now. Pennsylvania is struggling with this issue, but it is much bigger than one State can handle alone.

Request for this national solution does not come from a special interest group. It is about every single one of us and our families. About 80 percent, that's 8 out of 10, have already experienced a long-term care problem or will in the near future. So, at any time, any one of us could be added to that list, and it literally can take only a moment, just a split second, for an individual and in turn a family to be rendered helpless. As I said, about every single one of us will have an experience with long-term care.

Why has the need for long-term care come to the top of the national agenda and why is it so pressing? Why is it not going to go away? Well, there are a number of obvious and a number of not so obvious reasons for this.

First, advances in medical technology. This has made it possible for people to survive diseases, traumatic accidents, trauma during birth itself, which, a few years ago, we would not have survived.

In addition, we are an aging population, and with advanced age, obviously, we are more likely to need assistance. I saw some statistics just this year. It is estimated that 7.1 million elderly Ameri-

cans are disabled and need long-term care. By the year 2000, we expect that number to grow to 8.9 million, and by 2020 to 12.3 million. But, it is not just about older Americans. It is estimated that by the year 2000, 40 percent of functionally dependent Americans will be under 65 years old.

Another reason the issue has come to the forefront is because it is affecting business. By the year 2000, the U.S. workforce will be predominately female and minority. Women traditionally have taken care of their family members who have been sick. That is not expected to change.

So, when you are looking to balance having women in the workforce—and the country needs women in the workforce, business needs them—and you have the responsibility of caregiving in the home, it is tremendously stressful. It can result in loss of productivity, absenteeism, anxiety, and personal illness. But this is not just a “women’s” issue, it is a family issue, as I said. It becomes an economic issue. In this instance, it is our ability to compete in a global economy which is at stake.

Another big reason for the interest is the cost. As you indicated, the financial strain of a long-term illness on an individual and/or family can be devastating.

Insurance coverage, government or private, is usually available for hospitalization. Coverage for long-term care, however, is very limited and in some instances nonexistent. In the case of the public payers, as you indicated here, Medicare covers less than 2 percent. Medicaid covers about 42 percent of the total long-term care costs. And, in the case of Medicaid, as you indicated, persons using Medicaid were not poor to begin with but in a very short time, they are forced to “spend-down” their resources before entering the nursing home, and then they often leave an impoverished spouse behind in the community.

In Pennsylvania we do have a number of other public programs that are up and running. I am not going to detail them. I am sure you are going to hear about them from other witnesses.

The point I want to make about those, whether it is through the Pennsylvania Department of Aging and/or through the Department of Public Welfare, is that the need out there is exceeding the available resources. The money is just so limited. Again, we are looking to the Congress to help us with this.

As for private coverage, private insurance only covers about 1 percent of all long-term care at this point. That is what is currently available on the market. Often it is unaffordable for those who need it most. Policies are expensive, restrictive and often do not provide adequately for either nursing home care or home care. Where coverage exists, there is a limitation which is often quickly exceeded and then benefits cease. Then what are the families to do?

Actually, the majority of all long-term care is provided by family members or friends in the community rather than in an institution.

Can you just imagine—you visited a case recently Congressman, so you know how it is—the 24-hour responsibility of managing somebody at home? A lot of times a home caregiver may not live with the patient or the disabled person which further adds to the

burden. Or, they have to quit work. It is not unusual at all. Then you end up with impoverishment.

Available paid assistance to caregivers is limited, again primarily because people either cannot afford it or it is not covered through their private policy. At this point, I believe that about 15 percent of home care is actually provided by paid caregivers. In my travels, most caregivers say they do not want to be replaced, they just want a little bit of help.

There is one other point I wish to make, and that is about quality assurance. Whatever we do, whatever program we can ultimately develop through the Congress, I hope that there will be a provision for assuring quality.

In the case of home care, I obviously can't comment on nursing home or other facility-based long-term care. In the case of home care, we absolutely have to provide some minimum standards and then hold people accountable to them because, of course, home care is provided away from the public eye, to the most vulnerable among us. People cannot necessarily monitor their own care or they do not know what good care is. So, I would want to encourage you to look at that.

In conclusion, our Nation, as I said, really does need a comprehensive long-term care program. I want to show you what I would like to see in that program.

Long-term care should be available to all of us who need it regardless of our income, regardless of our age, across the generations.

We would like to see the financial risk of the program be spread as broadly as possible, possibly through a program like Social Security or Medicare. And, finally, the program should assist, not replace, family members providing care.

Whenever we talk about a national solution, the concern is always raised about the cost—how are we going to pay for it in light of our budget deficit and other competitive priorities?

My response is that I know it is going to be a major commitment but it is one we will have to make. We absolutely have to find a way to set up a long-term care program. I know we will. I really believe that this will happen at some point in the near future, because we are a very resilient and resourceful Nation. We have done incredible things in this century alone. It seems to me that we can figure out a way to care for our Nation's chronically ill, disabled, and aged members.

I look forward to working with both of you and the other Members of Congress toward that end. Thank you.

[The prepared statement of Ms. Pera follows:]

Pennsylvania Association of Home Health Agencies

1500 N. Second Street • Third Floor, Suite #2 • Harrisburg, PA 17102 • (717) 233-3363

Mary Kay Pera
Executive Director

STATEMENT ON THE NEED FOR LONG TERM CARE

PRESENTED

TO

THE HOUSE SELECT COMMITTEE ON AGING SUBCOMMITTEE
ON HEALTH AND LONG-TERM CARE

SEPTEMBER 15, 1989

MARY KAY PERA
EXECUTIVE DIRECTOR,
PENNSYLVANIA ASSOCIATION OF
HOME HEALTH AGENCIES

CO-COORDINATOR, PENNSYLVANIA
LONG TERM CARE CAMPAIGN

GOOD MORNING. MY NAME IS MARY KAY PERA. I AM EXECUTIVE DIRECTOR OF THE PENNSYLVANIA ASSOCIATION OF HOME HEALTH AGENCIES AND CO-COORDINATOR OF THE PENNSYLVANIA LONG TERM CARE CAMPAIGN. ON BEHALF OF THE FAMILIES WHO NEED LONG TERM CARE ASSISTANCE NOW AND THOSE WHO WILL NEED IT IN THE FUTURE, THANK YOU FOR YOUR INTEREST AND FOR HOLDING THIS HEARING. I AM HONORED TO PARTICIPATE.

OUR NATION FACES A NUMBER OF PRESSING ISSUES THAT ARE COMPETING FOR OUR ATTENTION. WE ARE HERE TO CONSIDER ONE--THE GROWING DEMAND FOR LONG TERM CARE. MILLIONS REQUIRE LONG TERM CARE AND THEIR NUMBERS ARE SWELLING. THE POINT I WISH TO MAKE IS QUITE SIMPLE: OUR COUNTRY NEEDS A COMPREHENSIVE LONG TERM CARE PROGRAM THAT COVERS HOME CARE AND FACILITY-BASED CARE, AND WE NEED IT NOW. PENNSYLVANIA IS STRUGGLING WITH THIS ISSUE, BUT IT IS BIGGER THAN ONE STATE CAN HANDLE. WE MUST SEEK A NATIONAL SOLUTION.

THE REQUEST FOR A SOLUTION TO THIS ISSUE DOES NOT COME FROM A SPECIAL INTEREST GROUP. LONG TERM CARE IS AN ISSUE THAT IS ABOUT EVERY ONE OF US--AND ABOUT OUR FAMILIES. EIGHTY PERCENT--THAT'S EIGHT OUT OF TEN U.S. FAMILIES--HAVE ALREADY EXPERIENCED A LONG TERM CARE PROBLEM OR WILL IN THE NEAR FUTURE. ANYONE OF US COULD BE ADDED TO THE "EIGHT OUT OF TEN" AT ANY GIVEN MOMENT.

IT LITERALLY CAN TAKE ONLY A MOMENT--JUST A SPLIT SECOND--FOR A LIFE FULL OF PROMISE TO BE RENDERED HELPLESS. OR IT CAN COME OVER A PERIOD OF TIME, LIKE A SLOW BURN. THOUSANDS OF

PENNSYLVANIA FAMILIES--MAYBE MILLIONS--HAVE STORIES THAT ARE BEYOND BELIEF--STORIES ABOUT THEIR MEMBERS WHO HAVE FALLEN VICTIM TO DETERIORATING DISEASES, ACCIDENTS OR TO TRAUMA DURING BIRTH ITSELF. YOU WILL HEAR FROM A FEW TODAY, AND, AS I SAID, ANY OF US HERE COULD HAVE A SIMILAR OCCURENCE IN OUR FAMILIES AT ANY TIME.

WHY HAS THE NEED FOR LONG TERM CARE RISEN TO THE TOP OF NATIONAL AGENDA AND BECOME SO PRESSING? WHY IS IT NOT GOING TO GO AWAY? THERE ARE A NUMBER OF OBVIOUS AND NOT SO OBVIOUS REASONS FOR THIS.

ADVANCES IN MEDICAL TECHNOLOGY

ADVANCES IN MEDICAL TECHNOLOGY HAVE MADE IT POSSIBLE FOR PEOPLE TO SURVIVE TRAUMATIC BIRTHS, ACCIDENTS AND ACUTE AND LONG TERM ILLNESSES.

DEMOGRAPHICS: THE AGING AND DISABLED

WE ARE AN AGING POPULATION, AND WITH ADVANCED AGE, WE ARE MORE LIKELY TO NEED ASSISTANCE. IN 1989, IT IS ESTIMATED THAT 7.1 MILLION ELDERLY AMERICANS ARE DISABLED AND NEED LONG TERM CARE. BY THE YEAR 2000, THIS NUMBER WILL GROW TO 8.9 MILLION, AND BY 2020 TO 12.3 MILLION. FURTHERMORE, IT IS ESTIMATED THAT BY THE YEAR 2000, 40 PERCENT OF FUNCTIONALLY DEPENDENT AMERICANS WILL BE UNDER 65 YEARS. IT IS ALSO PROJECTED THAT ONE IN TWO PERSONS AGED 65 AND OLDER CAN EXPECT TO SPEND SOME TIME IN A NURSING HOME DURING THEIR LIVES, AND ONE IN FOUR WILL SPEND A YEAR OR MORE.

THINK ABOUT THE IMPLICATIONS FOR OUR NATION OF THE 76 MILLION BABY BOOMERS WHO ARE MOVING THROUGH THE SYSTEM TOWARD RETIREMENT JUST AFTER THE TURN OF THE CENTURY. THESE PEOPLE ARE CONSTITUENTS WHO WILL BECOME INCREASINGLY MORE ORGANIZED AND MORE POLITICALLY ASTUTE. AT SOME POINT, THEY WILL USE THEIR NUMBERS TO VOTE FOR THOSE WHO SUPPORT THE KIND OF PROGRAMS THEY WILL NEED. PRESUMABLY, IT WILL NOT COST LESS TO INSTITUTE PROGRAMS AT THAT TIME. ISN'T IT BETTER--AND MORE ECONOMICAL--TO ANTICIPATE THEIR DEMANDS AND TO BEGIN NOW?

CHANGE IN THE WORKFORCE

EVEN BUSINESS IS BEING TOUCHED BY THE GROWING DEMAND FOR LONG TERM CARE. BY THE YEAR 2000, THE U.S. WORKFORCE WILL GROW ABOUT 1 PERCENT--MORE SLOWLY THAN AT ANY TIME IN OUR NATION'S HISTORY, AND IT WILL BE PREDOMINATELY FEMALE AND MINORITY. TWO-THIRDS OF NEW ENTRANTS INTO THE WORKFORCE WILL BE FEMALE.

WOMEN TRADITIONALLY HAVE BEEN THE PRIMARY CAREGIVERS, AND THAT IS NOT EXPECTED TO CHANGE. TODAY THE AVERAGE WOMEN CAN EXPECT TO CARE FOR CHILDREN FOR 17 YEARS AND PARENTS FOR 18 YEARS, WHEREAS IN 1900, PARENTS NEEDED CARE AN AVERAGE OF 4 YEARS.

BALANCING WORK AND CAREGIVING IS EXTREMELY STRESSFUL AND CAN RESULT IN ABSENTEEISM, ANXIETY, AND PERSONAL ILLNESS. BUT THIS IS NOT JUST A "WOMEN'S" ISSUE. IT IS A FAMILY ISSUE, AND BECAUSE OF ITS IMPACT ON BUSINESS, IT BECOMES AN ECONOMIC ISSUE, AND, IN TURN, A NATIONAL ISSUE.

CORPORATE AND GOVERNMENT POLICY-MAKERS, THEREFORE, HAVE NO CHOICE BUT TO BECOME INVOLVED IN FINDING A SOLUTION TO THE LONG TERM CARE CRISIS. A RESOLUTION IS NOT ABOUT ENTITLEMENT. IT IS A BOTTOM-LINE ISSUE. OUR ABILITY TO COMPETE IN A GLOBAL ECONOMY IS AT STAKE.

COST/COVERAGE

ANOTHER REASON FOR THE INCREASED INTEREST IN A NATIONAL LONG TERM CARE PROGRAM IS THE COST OF LONG TERM CARE. THE FINANCIAL STRAIN OF A LONG TERM ILLNESS ON AN INDIVIDUAL AND/OR FAMILY CAN BE DEVASTATING, AND FEW FAMILIES CAN PREPARE ADEQUATELY.

PUBLIC COVERAGE

INSURANCE COVERAGE (GOVERNMENT OR PRIVATE) FOR HOSPITALIZATION IS USUALLY AVAILABLE. COVERAGE FOR LONG TERM CARE, HOWEVER, IS VERY LIMITED AND IN SOME INSTANCES NONEXISTENT. MEDICARE COVERS LESS THAN 2 PERCENT OF NURSING HOME COSTS AND NO LONG TERM HOME CARE. MEDICAID COVERS ABOUT 42 PERCENT OF ALL LONG TERM CARE. MANY PERSONS USING MEDICAID FOR NURSING HOME COVERAGE, HOWEVER, ARE NOT POOR TO BEGIN. THEY ARE FORCED TO "SPEND-DOWN" THEIR LIFE SAVINGS AND ASSETS WITHIN A SHORT TIME OF ENTERING THE NURSING HOME, AND OFTEN LEAVE A REMAINING SPOUSE IMPOVERISHED.

THERE ARE A NUMBER OF OTHER PUBLIC PROGRAMS WHICH ARE AVAILABLE THROUGH THE PENNSYLVANIA DEPARTMENTS OF AGING AND PUBLIC WELFARE BUT ARE INADEQUATE TO MEET THE GROWING DEMAND FOR CARE. PROGRAMS PROVIDED THROUGH THE DEPARTMENT OF AGING INCLUDE

SUCH SERVICES AS PERSONAL CARE, HOMEMAKER SERVICES, AND HOME DELIVERED MEALS. THE FAMILY CAREGIVER PROGRAM PROVIDES RESPITE SERVICE IN SOME AREAS OF THE STATE TO FAMILIES WITH A MEMBER WHO HAS A LONG TERM ILLNESS. HOME CARE SERVICES ARE ALSO AVAILABLE THROUGH THE LONG TERM CARE ASSESSMENT AND MANAGEMENT PROGRAM (LAMP) AND THE TRANSITIONAL CARE PROGRAM. HOWEVER, AS I INDICATED EARLIER, THE NEED EXCEEDS AVAILABLE FUNDED SERVICES, WHICH RESULTS IN LONG WAITING LISTS IN SOME AREAS.

THE PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE HAS AN ATTENDANT CARE PROGRAM--A SERVICE THAT IS DESPERATELY NEEDED BY THE DISABLED IN ORDER TO SURVIVE. FUNDED WITH STATE AND FEDERAL DOLLARS, THIS PROGRAM COVERS CARE SUCH AS HELP WITH BATHING, DRESSING, GROOMING, ELIMINATION, EATING, AND OTHER ACTIVITIES ASSOCIATED WITH DAILY LIVING. THE SERVICE PERMITS PEOPLE WITH DISABILITIES TO PARTICIPATE IN SCHOOL, WORK, RECREATION, AND COMMUNITY LIFE. IT CAN MEAN THE DIFFERENCE BETWEEN INDEPENDENCE AND DEPENDENCE, AND LIVING IN THEIR OWN HOMES AS OPPOSED TO BEING INSTITUTIONALIZED. AGAIN, HOWEVER, THE NEED EXCEEDS AVAILABLE SERVICES.

AS FOR COVERAGE FOR FAMILIES WITH CHRONICALLY ILL CHILDREN, TYPICALLY THEY MUST RELY ON A PATCHWORK OF PRIVATE AND PUBLIC PROGRAMS.

IN PENNSYLVANIA THERE CURRENTLY IS A PROGRAM OPERATED BY THE DEPARTMENTS OF HEALTH AND PUBLIC WELFARE FOR TECHNOLOGY-DEPENDENT CHILDREN. THIS PROGRAM SERVES 64 CHILDREN, APPROXIMATELY 29 OF WHICH RECEIVE PUBLIC FUNDING.

PRIVATE COVERAGE

PRIVATE INSURANCE ONLY COVERS ABOUT 1 PERCENT OF ALL LONG TERM CARE, AND OFTEN IT IS UNAFFORDABLE FOR THOSE WHO NEED IT MOST. POLICIES ARE EXPENSIVE, RESTRICTIVE AND OFTEN DO NOT PROVIDE ADEQUATELY EITHER FOR NURSING HOME CARE OR HOME CARE. WHERE COVERAGE EXISTS, THERE IS A LIMITATION WHICH FREQUENTLY IS QUICKLY EXCEEDED AND THEN BENEFITS CEASE.

CAREGIVERS

THE GREATEST MAJORITY OF ALL LONG TERM CARE IS PROVIDED BY FAMILY MEMBERS OR FRIENDS IN THE COMMUNITY RATHER THAN IN AN INSTITUTION.

CAN YOU IMAGINE THE PHYSICAL AND EMOTIONAL STRAIN OF THE DAY-TO-DAY CARE OF A LOVED ONE WHOSE CONDITION IS DETERIORATING? THE CAREGIVER MUST LIFT, TURN, BATH, AND FEED THE INCAPACITATED PERSON 24 HOURS-A-DAY. IN ADDITION, THE CAREGIVER OFTEN MUST WORK AND MAY NOT LIVE WITH THE DISABLED PERSON, FURTHER ADDING TO THE BURDEN. OR THE CAREGIVER MAY HAVE TO QUIT WORK; IMPOVERISHMENT IS NOT USUAL. OVER THE LONG HAUL, IT IS A TREMENDOUS BURDEN.

AVAILABLE PAID ASSISTANCE TO CAREGIVERS IS LIMITED, PRIMARILY BECAUSE OF INADEQUATE FUNDING. ONLY 15 PERCENT OF HOME CARE IS PROVIDED BY PAID HOME CARE WORKERS, INCLUDING PROFESSIONAL NURSES AND THERAPISTS, AS WELL AS PARA-PROFESSIONAL WORKERS, SUCH AS HOME HEALTH AIDES, HOMEMAKERS AND COMPANIONS. AS FOR PAID ASSISTANCE, MOST CAREGIVERS SAY THEY DO NOT WANT TO BE TOTALLY RELIEVED OF THEIR DUTIES; THEY JUST NEED HELP.

QUALITY ASSURANCE IN HOME CARE

QUALITY ASSURANCE MUST BE ADDRESSED IN WHATEVER LONG TERM PROGRAM WE ULTIMATELY DEVELOP. I AM NOT PREPARED TO COMMENT ON QUALITY ASSURANCE IN NURSING HOMES OR OTHER FACILITY-BASED LONG TERM CARE, BUT I DO WANT TO MAKE A FEW OBSERVATIONS ABOUT QUALITY ASSURANCE IN HOME CARE.

THERE ARE A NUMBER OF COMPELLING REASONS FOR ESTABLISHING QUALITY ASSURANCE PROGRAMS IN HOME CARE. FIRST, HOME CARE IS PROVIDED OUTSIDE THE PUBLIC EYE, OFTEN TO THE MOST VULNERABLE AMONG US: PEOPLE WHO ARE SICK, DEPENDENT, AND UNABLE, EITHER BECAUSE OF THEIR INFIRMITY, LACK OF KNOWLEDGE, OR OUT OF FEAR, TO MONITOR THEIR OWN CARE AND TO ENSURE THAT IT IS OF ACCEPTABLE QUALITY.

SECOND, THERE HAS BEEN AN UNPRECEDENTED INCREASE IN THE NUMBER AND TYPES OF HOME CARE AGENCIES, MANY OF WHICH ARE NOT REGULATED BY LAW. THERE ALSO HAS BEEN AN INCREASE IN THE NUMBER OF SELF-EMPLOYED INDIVIDUALS PROVIDING IN-HOME CARE. PUBLIC AND PRIVATE PAYERS, IN STRUGGLING TO CONTAIN HEALTH CARE COSTS, MAY DENY NEEDED CARE AND, IN DOING SO, COMPROMISE QUALITY.

QUALITY ASSURANCE IN HOME CARE MUST BE VIEWED AS A TOP PRIORITY AND THE GROWING PUBLIC EMPHASIS ON IT IS WELCOMED. THERE IS AN URGENT NEED TO REACH A CONSENSUS ON ACCEPTABLE STANDARDS FOR HOME CARE--STANDARDS THAT MUST BE MET BY EVERY HOME CARE PROVIDER AND THAT CONSUMERS AND PAYERS WILL RECOGNIZE AS SIGNIFYING A QUALITY SERVICE.

CONCLUSION

OUR NATION NEEDS A COMPREHENSIVE LONG TERM CARE PROGRAM THAT COVERS HOME CARE AND FACILITY-BASED CARE FOR CHRONICALLY ILL CHILDREN, THE DISABLED, AND THE ELDERLY. SUCH A PROGRAM SHOULD BE AVAILABLE TO ALL OF US WHO NEED CARE, REGARDLESS OF AGE OR INCOME. THE FINANCIAL RISK OF THE PROGRAM SHOULD BE SPREAD AS BROADLY AS POSSIBLE, PERHAPS THROUGH A PROGRAM LIKE SOCIAL SECURITY OR MEDICARE. FINALLY, THE PROGRAM SHOULD ASSIST, NOT REPLACE, FAMILIES AND OTHER INFORMAL CAREGIVERS.

EIGHTY-FOUR PERCENT OF THOSE SURVEYED IN A 1989 NATIONAL POLL BY LOU HARRIS AND ASSOCIATES SAID THEY SUPPORT A NATIONAL LONG TERM CARE PROGRAM FOR THE ELDERLY AND DISABLED. CONCERN IS BEING EXPRESSED BY SOME, HOWEVER, THAT IT WILL BE TOO EXPENSIVE IN LIGHT OF OUR BUDGET DEFICIT AND OTHER COMPETITIVE PRIORITIES.

OUR RESPONSE TO THAT IS: WE KNOW IT IS GOING TO BE A MAJOR COMMITMENT. BUT WE MUST FIND A WAY. WE NEED A COMPREHENSIVE LONG TERM CARE PROGRAM. WE WILL FIND A WAY. HOW DO I KNOW THAT? WELL, WE ARE A RESILIENT AND RESOURCEFUL NATION. IN THIS CENTURY ALONE, WE HAVE SURVIVED THE CRASH OF THE STOCK MARKET. WE HAVE SEEN THE INVENTION OF TELEVISION, THE COMPUTER, AND THE MICRO-CHIP. WE HAVE FOUND CURES FOR COUNTLESS DISEASES. WE HAVE NOT ONLY LEARNED TO FLY, WE HAVE BEEN TO THE MOON. SURELY WE CAN FIGURE OUT HOW TO CARE FOR OUR NATION'S CHRONICALLY ILL, DISABLED, AND AGED MEMBERS.

WE LOOK FORWARD TO WORKING WITH YOU AND THE OTHER MEMBERS OF
CONGRESS TOWARD THAT END.

Mr. BORSKI. Thank you. We will hold questions until all of these panelists complete their statements. So, Diane and Tim, if you want to go next.

STATEMENT OF TIM AND DIANE KAISENGER

Ms. KAISENGER. Good morning, Mr. Borski and Mr. Manton. My name is Diane Kaisenger, and this is my husband Tim. We are here on behalf of our son, Timmy, who is a 9-year-old boy.

Tim and I have been married for 10 years. We have two children, Timmy and Kristen, and we live in Bridesburg, in Northeast Philadelphia. Tim works as a roofer and I take care of our children at home.

A little over a year ago, Tim and I noticed that Timmy was not himself. He was listless and not interested in playing. From the time he was born, he was a healthy, active child. He loved sports and especially basketball. This particular week he was lying around the house. He said that he had trouble seeing. That Sunday at church I noticed that he could not read.

Mr. KAISENGER. We noticed that he couldn't read from the Apostle's Creed. We made an appointment with the ophthalmologist that week. The ophthalmologist did a thorough 1½ hour examination. He said that one of Timmy's eyes was dilated more than the other eye and Timmy had trouble moving his eyes upward when he put the light up to the ceiling. He could not do it.

The next day we met with the head of neurology at Children's Hospital in Philadelphia. After only a short examination, he told us Timmy had a brain tumor but he could not say how large it was or how much damage it had done.

Timmy was operated on over a year ago and he has had five operations since. He is fed intravenously, a shunt drains fluid from his head and a tracheotomy tube ensures that he breathes properly. He has never fully awakened from that first operation to remove the tumor. The tumor itself was much larger than the doctor had expected. It has reached many parts of Timmy's brain. The team of doctors at Children's Hospital suspected that it had been growing for years. We had no idea that Timmy was so sick. And we have no indication if, or how fast, the tumor will grow back.

Ms. KAISENGER. Timmy needs 24-hour care. He is not at home where we want him to be with his family and friends. He has made great progress in recent months. He smiles when you talk to him. His 7-year-old sister, Kristen, taught him to mouth the words, "I love you."

Timmy cannot be left alone. His throat needs suctioning frequently. He needs to be turned, his muscles need to be moved, massaged, and stretched and his diaper must be changed. We are not sure how much Timmy understands about what has happened to him. But his progress at home has been undeniable.

Since Timmy came home from the hospital on February 8, we have exhausted all of our coverage under the Roofer Union's major medical coverage, a \$75,000 maximum. We now have a contract with Blue Cross to cover Timmy's home care in lieu of the remaining hospital coverage for Timmy. But if for some reason Timmy's

condition were to become worse and he had to be hospitalized, the contract would become null and void. I don't know how we will pay for Timmy's care when the hospital coverage limit is reached. I don't know what we will do if Timmy is hospitalized or needs further surgery. Already we will be paying medical bills for the rest of our lives.

We feel as though we should try to take care of our son at home. We want to take care of him and give him the best stimulation to help him improve, but we need support. Twelve hours of constant care every day is very draining even when the whole family pitches in.

Aside from the physical strain, the financial burden is astronomical. Nursing care for Timmy through the night is \$540 for a 12-hour shift. That is almost \$4,000 a week, and over \$15,000 a month. We are grateful for the donated machines that help Timmy survive. They would have cost almost \$1,500 and weekly supplies alone cost almost \$200. And, as I said before, we don't know what will happen when the insurance coverage runs out. This is the heaviest burden on us right now.

We are here to let you know about our experience and we hope that by telling our story, we will contribute to a plan to help families like ours. Long-term illness devastates families physically and mentally. We want to stay together, but in many ways, the health care policies of this country and insurance companies make that very difficult. Please develop a long-term care insurance plan to protect us and others like us from devastation.

Mr. BORSKI. Thank you very much for your testimony. I know it was very difficult. I really do appreciate your coming here. I think people throughout the Nation need to hear these kinds of stories. Again, we greatly appreciate your coming.

Mr. Keane.

STATEMENT OF WILLIAM L. KEANE

Mr. KEANE. Congressman Borski, Congressman Manton. I am grateful for the opportunity to be a witness on the critical issue of long-term care in the United States.

As you have so eloquently already been told, it is an issue that strikes all ages groups and generations; an issue which transcends the current media obsession with drugs and AIDS and budget balancing; it is an issue that calls not for short-term, knee-jerk, political reactions, but proactive dynamic leadership that will forge a fair, long-term policy and system of implementation. In essence, the issue of long-term care strikes at the heart of the American ethic: How do we guarantee our commitment to preserve the freedom and dignity of every citizen throughout his or her life span?

I have had the opportunity to experience this issue from several different perspectives. Currently, I am the Assistant Administrator of the St. Lawrence Rehabilitation Center in Lawrenceville, New Jersey, where we have a short-term skilled nursing unit and respite care program for the elderly. I have experienced firsthand the problems of regulation, reimbursement and staffing that challenge the development of appropriate services for the elderly. Further-

more, until 1985, I was the primary caregiver for my mother and her sister, who both died from Alzheimer's disease.

My mother dwindled for almost 10 years in a Delaware County nursing home before she died, at a private pay rate of nearly \$20,000 a year, nearly bankrupting my father's hard-earned, post-Depression savings. I might add that my father did not entertain the legal manipulation of transferring assets in order to prematurely qualify for the Medicaid "spend-down" limits. In my aunt's care, my mother had already given away her assets by the time I assumed responsibility for her care, and was eventually admitted to a Medicaid nursing home in Philadelphia. In my family and in numerous other situations that I have observed in Philadelphia and the surrounding counties, the respite care option of permanent institutionalization has been scarce or inappropriate, and most nursing home facilities are not equipped with the staff, physical environment, or regulated policies to provide for the true needs of dementia patients.

But primarily, I am here today as the President of the Alzheimer's Association of Greater Philadelphia. We were founded in 1980 as a voluntary nonprofit organization dedicated to assisting the victims of dementia, their families, and other caregivers. Our efforts cover the five-county region and include programs in education, referral, patient and family service, public advocacy, and research. Through statistics developed by the National Institutes of Health, we estimate that there are more than 60,000 victims of Alzheimer's disease in the greater Philadelphia area. And, with every generation impacted, we estimate there are an average of three families members who are significant caregivers per patient and who have been dramatically affected in some way by the disease. In sum, that represents nearly a quarter of a million citizens in this region whose lives have been physically, emotionally or financially devastated by this unknown, incurable disease of the brain.

With an average life span, from time of diagnosis, of 2 to 20 years, the Alzheimer's victims and their family system must have a long-term plan of care that, with an adequate system of respite services, strives to keep the patient functioning at home as independently as possible, for as long as possible. When institutionalization becomes the appropriate action, it should be in a safe and dignified facility that can care for the needs of dementia patients. Although it has been estimated that half of all nursing homes residents have Alzheimer's disease, most of them really do not require the skilled nursing care for which the facility has been licensed by the Department of Health.

Ultimately, we believe that the challenge facing all of us is one of planning and fairness. Planning to assure the readiness of a cost-efficient, appropriate system of long-term care for Alzheimer's patients and their families. And fairness to ensure the financial support that is adequate for this growing population. In marketing terminology, Alzheimer's disease is competing with other diseases and other long-term illnesses that perhaps have been more skilled at getting your attention and your funding of late.

The family caregiver today is truly one of America's unsung heroes who is literally living the 36-hour day of providing for the care and dignity of his or her loved one. Entirely supported by pri-

vate donations, our Philadelphia Chapter this fall is instituting a caregiver training series to help the family caregiver with practical information in the task of caregiving at home. We would not be able to reach the people who could benefit from these programs if we did not provide a subsidy for a home care companion to sit with the patient while the family member attended our session. Indeed, many of our callers cannot even get to a support group for emotional support, much less to a public forum such as this, because they do not have access or cannot afford any outside support services. Indeed, many of these primarily spouse caregivers become the "other victim" of Alzheimer's disease, such as my own father who died of depression and stress 2 years before my mother.

The Alzheimer's Association, representing over 4 million people with Alzheimer's disease and related disorders and their families and caregivers, is particularly sensitive to the unmet need for home, community-based and facility-based long-term care and services. Long-term care affects all age groups, and services should be provided to and paid for by all Americans. The Greater Philadelphia Chapter supports the "National Campaign to Conquer Alzheimer's disease" and the Long-Term Care Campaign as formally presented to the Congress this past April. The details of these proposals have been included with my testimony.

In conclusion I would like to compliment the concern and work of the committee and I urge you to continue to listen to the quiet heroism and needs of these caregiving families. It is now my pleasure to introduce to you one of those caregivers. Jerry Gibbons' wife showed the symptoms of Alzheimer's disease nearly 5 years ago at the age of 49. Mr. Gibbons is a resident of Chester County and a member of our Central Philadelphia Support Group near where he works. While he might remind you of his independent means of financing his wife's care at this time, the risk is that there could be no resources for him later on in his life when he might need some resources.

However, I must remind you that Mr. Gibbons' independent commitment to his wife's care is typical of so many families in this Nation who are giving so much in standing by those that they love. Mr. Gibbons certainly merits our full attention and a long-term commitment to stand by him. Thank you.

[Supplemental material submitted by Mr. Keane follows:]

THE LONG TERM CARE CAMPAIGN ...FACT SHEET

WHAT IS LONG TERM CARE?

Overview

- Long term care is assistance with regular, everyday activities, such as eating, bathing and dressing for those with a long term, chronic illnesses.
- Eight of ten American families have already experienced a long term care problem, or will in the near future.
- In 1989 an estimated 7.1 million elderly Americans will need long term care and 1.6 million of them are now in nursing homes. One in two persons 65+ will spend some time in a nursing home in their lifetime, and one in four will spend a year or more.
- The average annual cost of a nursing home stay exceeds \$25,000. The total national cost for nursing home care in 1987 was \$41.6 billion; more than half of this was paid by families and patients out of their own pockets.
- Almost five in ten elderly living alone will spend down their income and assets to the poverty level after only 13 weeks in a nursing home.
- The vast majority of long term care is provided in the community by family members and friends. One-third of family caregivers live in poverty, and among those who work, many have had to take time off or quit their job.
- Medicare covers less than 2 percent of long term care costs and private insurance only 1.4 percent. Medicaid (welfare) is available only to the impoverished and then, generally, for nursing home care.
- A national, universal, social insurance program is needed to provide long term care protection to Americans of all ages, regardless of income.

ALZHEIMER'S ASSOCIATION LONG TERM CARE PRINCIPLES FOR FEDERAL LEGISLATION

The Alzheimer's Association, representing over 4 million people with Alzheimer's Disease and related disorders and their families and caregivers, is particularly sensitive to the unmet need for home, community-based and facility-based long term care and services. Long term care affects all age groups and services should be provided to, and paid for, by all Americans. The Association believes there is immediate need for a federal, universal and comprehensive long term care social insurance program that is "dementia friendly." The Association supports the following principles for long term care reform:

BENEFITS/ELIGIBILITY

1. Eligibility for long term care services in all settings should be extended to all individuals who need them, regardless of age, income, marital status or informal social supports.
2. Eligibility should go beyond traditional measures of disability to include functional, cognitive or behavioral limitations, including the need for supervision because of risk to safety or health or the need for verbal reminding or physical cuing. Eligibility determination should be flexible enough to reflect individual situations.
3. Both public and private long term care insurance programs must cover care provided to Alzheimer's Disease and related disorders patients.
4. Benefits should provide needed services at all levels of care, ranging from a comprehensive system of home and community-based services to facility based services. Services should be provided in such a way as to maintain and enhance personal independence in the community and in the setting preferred by the beneficiary and family.
5. The long term care benefit package should allow maximum flexibility in meeting individual client needs. Direct and indirect services and supplies including items needed to maintain patients at home such as consumable care supplies, should be covered benefits.
6. The program should consider the needs of both beneficiaries and caregivers as appropriate recipients of services. Patient socialization, caregiver respite and other support services should be covered in all settings.
7. Facility based care should be covered in its entirety, regardless of the length of stay.
8. The program should assist families and other informal caregivers. Families should be a primary part of care coordination and beneficiary and family care preferences must be considered in planning and coordinating care. Care coordination should also support, rather than supplant, client and family decision making. There should be no disincentives to family participation; nor should providing informal care be a prerequisite for formal care.

9. Adequate education and training for long term care providers is an essential component of care; provider training must incorporate instruction specific to the care needs of dementia patients. The long term care program should also offer education and training for informal caregivers.
10. The program should ensure high quality care. In order to help ensure quality and access, programs should be monitored, and providers should be carefully screened, well trained and adequately supported and compensated. Efforts to enhance meaningful quality assurance should take special account of the situations faced by patients with Alzheimer's disease or a related disorder.
11. The program should ensure access to services for all. No patient or family should be denied access to information or services because they refuse to relinquish control of care planning to an agency, professional or team.
12. Research should be conducted on more accurate measures of disability and on the adequacy of services to meet patient and family long term care needs.
13. Special provisions should be made to assure that those who lose cognitive function maintain rights to make appropriate care and treatment decisions to the extent of their ability and that their legally designated agents maintain rights to make decisions for them to the extent necessary due to their cognitive impairments.

FINANCING

14. The long term care program should be based on traditional social insurance principles and spread the financial risk as broadly as possible. Its structure should not require the impoverishment of individuals or families.
15. Basic long term care coverage should be made available to all eligible individuals. The program should provide benefits to members of all generations and these costs should be shared equitably across generations. Private insurance may offer supplemental coverage, and standards should be set to protect consumers.
16. Means-tested programs such as Medicaid should not serve as the basis of the federal long term care program; coverage and financing should be uniform throughout the nation and should not stigmatize those in need.
17. The new public program should be supported through sources of financing that are as progressive as possible.
18. Protection from out-of-pocket costs for low and moderate income persons should be provided.
19. Cost containment should be built into the program. The public costs of the program should be minimized while meeting consumer's needs.

Mr. BORSKI. Mr. Gibbons.

STATEMENT OF JERRY GIBBONS

Mr. GIBBONS. My name is Jerry Gibbons and I am here to tell you about my wife, Molly. Molly and I have been married for 31 years and we have three adult children. We live in West Chester, Pennsylvania.

Molly was always a super mother, an excellent homemaker and a great wife. She contributed to the finances as she worked in a clerical capacity with a large mail order house. She drove a car and she was just a very competent, independent person. But, about 5 years ago, she started doing some peculiar things. She misplaced a lot of things. She misplaced keys to the car. She would get into the car and not know—of course she had driven for years—where the ignition switch was to put the key in. She would go run an errand and then come back and park the car at the bottom of the driveway, like she didn't know where the car belonged. At work she misplaced things. She was disoriented about tasks that she had heretofore done quite well.

Next year, the situation got worse. She was being treated for some menopausal problems and the doctor recommended surgery. After surgery, the mental situation became worse. We decided that we should take the keys to the car away from her, and surprisingly she didn't object to that at all. She had to give up her job. Finally, that year she was diagnosed with Alzheimer's disease, the progressive, irreversible brain disorder for which there is no cure.

Alzheimer's disease attacks the brain very slowly. When it started with Molly, she just did the little odd things that I had mentioned. Now, it has progressed to advanced stages and she can no longer dress herself. She is unable to do some of the basic functions. She is unable to feed herself. She cannot be left alone. I am trying and want to take care of her as long as I can at home, and I know as the disease progresses this will be increasingly difficult.

To give you an idea of the 36-hour day Bill mentioned, I get up at 5 o'clock in the morning, get her washed and dressed and give her her breakfast. I take her to my son's apartment who lives nearby and he goes by an adult day care center. He drops her off at 7:30 a.m. and by 5 o'clock at night, he picks her up and since I am working in Philadelphia and time commitments and whatnot, I don't get home until 7:30 or 8 o'clock. And, I have a homemaker health aide agency that provides health aides between the time of 5 and 8 o'clock at night, at which time I take over. On some weekends we have health aides come into the house and take care of her so I can do basic errands and some various kinds of chores that need to be done around the house.

I guess I am fortunate to have the resources to provide these kind of services because the burden of these costs is affecting me greatly. I would guess my income is above average. I have been a CPA in private industry for some 25 years. My wife worked for a number of years and we planned and saved for retirement. We sent our kids to college and I participate in a retirement savings plan, a 401K Plan and I have contributed to an IRA plan.

Yet, with Molly's illness, I am not sure where I am going to be financially. I am currently spending \$1,700, \$1,800 a month for various adult care and home health aides for weekend relief. Since the beginning of her illness, I have spent somewhere in the area of \$35,000. These costs are going to increase with time. Because Molly is relatively young, we could be struggling with the emotional, physical and financial burden of the disease for another 20 years.

I am not looking for a government handout for Molly's care, but certainly paying for Molly's medical costs and providing for my own retirement will be a challenge. My future is at best unclear financially. I just can't imagine how the average American family can cope with a long-term illness of this nature. And, I hope that Congress will be able to develop a policy to help American families who struggle with Alzheimer's and other catastrophic illnesses. I would think it would be a very sound investment in the government—in the Nation's future. Thank you.

Mr. BORSKI. Thank you very much. Mr. and Mrs. Kaisenger, could you tell me, the Roofers' insurance plan that you have, is it a good one?

Mr. KAISENGER. Yes, better than most.

Mr. BORSKI. Would you have had any thought beforehand that you would not be covered for anything?

Mr. KAISENGER. No. I kind of assumed that I would never have a problem with medical, you know, until Timmy got sick.

Mr. BORSKI. Mr. Gibbons, can I ask you the same question? Did you think you had a pretty good policy? Were you aware that you would not be covered for this type of illness?

Mr. GIBBONS. As a matter of fact I was not aware. I had investigated with our company whether Timmy's care would be covered and initially was told that it would. And, I heard so many horror stories about people who went into hospitals expecting to—or into nursing homes—expecting that they would be covered and found out that term, "custodial" precluded the thing. I pushed our people and found out that ours in not covered. And, we have what is considered a very progressive plan.

Mr. BORSKI. That is the point that I want to make. I think that most people when they think about this kind of illness hitting—first of all I don't think we believe that it will ever hit us. I think most people think in a positive vein. But, also, we think that if we have a decent job and pay into a good policy that our health care needs are going to be met and they are not. I think that is one of our problems generally as a Nation. That until it affects us directly we don't really give much thought to whether we are going to be covered for these kinds of illnesses.

I think that the examples brought before us here today are clear. I appreciate very much your taking the time and effort to come and explain to us what happens to you when this kind of illness hits home. It is devastating. Besides the emotional devastation that you suffer and the actions that you must take personally to protect your loved ones, the pure financial aspect of this kind of illness is just inconceivable. There absolutely has to be something done about it. Can you—and, perhaps Ms. Pera and Mr. Keane can answer this too. Mr. Gibbons, you said you spent around \$30,000 so far out of pocket. Over how long a period is that?

Mr. GIBBONS. I would say that is over the last year and a half to 2 years—when we decided that she really couldn't be left alone. Initially, she could be left alone for a few hours a day, but then it finally, gradually got to a point that we just couldn't leave her alone. Then, of course, the cost escalated and I would say that it is about over a 2-year period of time.

Mr. BORSKI. And you think that is going to continue to rise?

Mr. GIBBONS. I am sure it will.

Mr. BORSKI. Without question. Does your insurance cover anything, any part?

Mr. GIBBONS. Any part of that care? No.

Mr. BORSKI. That is totally out of your pocket.

Mr. GIBBONS. Totally out of my financial—

Mr. BORSKI. And, fortunately, as you said, you have the means to keep that up for at least a while. Is there a point where you will not be able to meet those needs?

Mr. GIBBONS. I got to thinking when I heard Bill mention \$20,000 nursing home costs, I have heard \$36,000 nursing home costs, escalating at a rate significantly higher than inflation. It wouldn't take very many years to where, yes, I would be in a difficult financial situation.

Mr. BORSKI. Tim and Diane, do you know how much it has cost you thus far out-of-pocket? Are there estimates that you have?

Ms. KAISENGER. Out of pocket? Well, right now we are pretty fortunate that Blue Cross has picked up for homecare. But they do have a contract and that contract is renewable every 3 months. But, the contract right now is down to 220 home care days that they will pay for nursing. If he goes into the hospital, it is 110 hospital days and after that he doesn't have any more Blue Cross. So far we haven't had to put too much out of our own pocket because they are picking up for supplies and equipment at home.

Mr. BORSKI. The normal expenses I would expect would be pretty high themselves, but you have some coverage at this point.

Ms. KAISENGER. Whenever they are finished with their part and their policy, then it would be up to us to pay for everything.

Mr. BORSKI. Has anyone given you any idea of what that might cost you?

Ms. KAISENGER. Well, if we were to continue nursing care, Timmy would continue to need the 12-hour care. That is \$3700 a week.

Mr. BORSKI. Thirty-seven hundred dollars a week.

Ms. KAISENGER. A week, for 12 hours a day.

Mr. BORSKI. And, the other 12 hours you do yourself?

Ms. KAISENGER. Yes.

Mr. BORSKI. Is that correct?

Ms. KAISENGER. Yes. And, for equipment and supplies, Timmy's bed, formula for his gastrostomy tube, and I know that it is around \$350 a month for the cases of that that we need. Then, above and beyond that it is just diapers, and all the medical needs. So, I couldn't even imagine paying for all of that.

Mr. BORSKI. So, thus far in your case, your insurance policy has pretty much covered, but you do see some point in the near future where it could just be gone.

Mr. KAISENGER. We have a hundred days.

Ms. KAISENGER. We are close.

Mr. KAISENGER. We are very close to a problem.

Mr. BORSKI. What happens then?

Mr. KAISENGER. I don't know.

Ms. KAISENGER. We don't know. We can apply for a State model waiver, but then we have to make out an application for that and wait to see if we are accepted, if Timmy is accepted.

Mr. KAISENGER. But, in the meantime, that will be our responsibility. There is no way I could handle it, to be honest. I work for a pretty good union and I make a lot of money compared to most people, too. But in no way could I possibly afford any of that.

Mr. BORSKI. You don't get \$3,700 a week?

Mr. KAISENGER. No. More like \$400. There is no way I could cope.

Mr. BORSKI. Is there any way that your son would pick up care or if someone would pay if he was institutionalized rather than kept at home?

Ms. KAISENGER. Well, we did go through that with Blue Cross telling us that it would be less expensive for them to put him in a nursing home than to provide his home care for the nursing, equipment and supplies. But, we put in an appeal. We asked, for the kind of care that he would be getting in a nursing home, couldn't he be given the higher quality care that he is getting at home and that I know he is getting? Then they came up with a new contract and they did agree to keep him at home and pay for it.

Mr. BORSKI. If Timmy gets worse and his 12-hour support system that you have, and it is not covered anymore, I assume then that you would have to institutionalize him?

Ms. KAISENGER. It might be a possibility. If he doesn't progress from where he is now; if he still has the tracheal tube; if there is no coverage for him at home, then I would be forced to do—we would be forced to do 24-hour care.

Mr. KAISENGER. I would have to quit my job. I would have to take the other 12-hour shift from Diane. It is hard enough for Diane to do the 12 hours. She goes—as soon as the nurse comes she goes right to bed, she is beat. There is a lot of work involved, plus taking care of the house, the bills, and all the records and all this stuff, the insurance policies she has got to keep track of. I don't know how she does it now.

Mr. BORSKI. If the insurance stayed on it is still a mammoth job.

Mr. KAISENGER. It is staggering, the amount of work it requires. It is impossible, and I don't know how she does it.

Mr. BORSKI. Twelve hours a day, I think I could rightly say, is 12 intense hours that you are watching and caring constantly. It is not like you are going out shopping and leaving him for a little bit of time. You have to be there full-time.

Ms. KAISENGER. Plus do physical therapy, keep up the stimulation.

Mr. BORSKI. I was trying to get to—I wonder what happens if your insurance runs out and if he gets a little worse and has to be institutionalized, where does Medicaid take over? When does the State start to chip in?

Ms. KAISENGER. We would have to apply for Medicaid assistance. And, I was told to do that now for some of the outstanding hospital

bills because Blue Cross pays 80 percent and we are responsible for 20 percent of the still unpaid hospital bills. So, I was told to check into that soon.

Mr. BORSKI. So, that 20 percent, I take it, is pretty high.

Ms. KAISERGER. Yes. We are talking about his surgeries and doctor visits, so it is up there. The bills that are still lying around are very expensive and I have no idea how I am going to get through those.

Ms. PERA. Congressman, I have some knowledge about the Medicaid Waiver Program for technology-dependent kids. Right now Pennsylvania does have approval for a Federal waiver to cover home care, around the clock, up to 16 hours a day. Here is the catch. Right now their approval is for 100 kids, and they are serving somewhere around 64. Up to 100 is it, and beyond that there is nothing. There is Medicaid coverage for part-time intermittent care on a per-visit basis. You could have a daily visit for up to 28 days—the first 28 days of care—but beyond that, again there is a restriction.

The coverage in that program is well under the cost for providing that service which makes it very difficult for a lot of providers to participate—you know, it's like subsidizing what should be an entitlement. Again, it's a program that is in place but it is limited. It is not adequate to meet the needs, the growing needs.

Mr. BORSKI. I would like to ask you and Mr. Keane, too, the earlier question I asked these folks. In your experiences, are people just shocked when they find out they are not covered?

Ms. PERA. Oh, absolutely.

Mr. KEANE. Absolutely. I think that the current generation of senior citizens was, if I can use the phrase, "anesthetized" back in the sixties when the Medicare and Medicaid laws were passed with much pomp and circumstance. You have to realize that the average American that is 70 years old today was about 45 when those laws were passed. For 25 years they tended to believe that there was high-tech medical care as a right for every American, that it would be available when they needed it in their old age, and that it wouldn't cost them anything. Then it started to cost them small deductibles, but there was always that assumption that it would include long-term care.

And, I think, as you well know, you are seeing a lot of backlash now over the catastrophic legislation. There were an awful lot of senior citizens I know who felt that this was going to be a panacea for their long-term health care needs. Later they realized that they were just paying for the catastrophic medical acute care element and not really addressing any of their long-term care needs. So, there is still a lot of shock that goes on with a lot of senior citizens, a lot of elderly caregivers that we interact with in our Chapter office who don't understand the system and how it really works. It is quite devastating when they have to start paying for long-term care and find themselves literally going bankrupt in a couple of years.

Ms. PERA. It is true. I reiterate that. Families just can't believe it. What, I've got my Medicare. We deal with that all the time in home care. There is Medicare for acute services, short-term, part-time, intermittent. I mean we are talking short-term at this point.

And, they just can't believe it. You asked what happens when there is nothing, no coverage. Families try to hang on and they deteriorate. The patients deteriorate. The caregivers deteriorate.

Mr. BORSKI. I think the point should be made that, with the examples we have here today, it is not just the elderly that find themselves in this situation.

Ms. PERA. No. Absolutely not.

Mr. BORSKI. It is not just retirees who think that Medicare or their insurance is going to take care of things. If you are a working man or a businessperson, you believe that you have got good solid coverage for anything that will come along then and you find that you don't. So, I think it should be noted that it is not, as the examples mentioned, just for the elderly but for all Americans in all the social strata.

Ms. PERA. Congressman, you know the disabled adults, those people count on dependent care for survival. They need somebody to come in. If it is not available for them and by the time you have been through a long-term disability, you have expended everything. So, they simply have nobody. They can't make it at all.

Mr. BORSKI. Congressman Manton.

Mr. MANTON. Thank you, Bob. I am very pleased to come down from New York. I represent the so-called "Archie Bunker district," in Queens, and looking around, it looks like my district a lot. Of course, none of us is Archie Bunker. I think we all have a little of Archie in us, but I think he is unique.

When Bob asked me to come down I was very happy to do so. We serve together on the Aging Committee and we also serve on the Merchant Marine Committee together, and he has been in my district where we had similar kind of hearing on other issues affecting the aging.

Mr. and Mrs. Kaisenger bring to mind that we are not only dealing with the senior citizens. I have that kind of district. I think we are the twelfth highest number of senior citizens out 435 districts in the United States, and we sometimes tend to focus more on the elderly and not realize that anyone of us, young or old, either ourselves or our families can be victimized by the need for this kind of long-term care that we don't provide.

I just returned from Europe where I visited a number of not only Western European countries, but some Eastern Block countries too. Our last stop was in Ireland, where my folks come from. We were having lunch at the Foreign Ministry in Dublin and I ran into a fellow I knew from New York.

He had been the Irish Counsel General in New York City before returning to Ireland where he now is sort of the liaison with the European Economic Community. He said to me, Tom, you know the United States is a great country, but you really have to do something about comprehensive health care. You are such a rich and affluent and great country and a great defender of rights and liberties all around the world. But he said, you really are not even up to par with Ireland in many ways when it comes to providing that kind of care. He said you really ought to do something about it.

I think it is important that we have hearings like this. When we hear that we are, along with South Africa, on the short end of the

stick as far as providing the kind of care we are talking about here today. I am not considered a liberal or a radical by any means, even within the Democratic Party, of which I am proud to a member, but when we think about spending some \$500 million on one bomber, on the stealth bomber, I am not sure it can even fly very well at this point. But, when we have this kind of need crying out for attention by our Congress and by the Government, I salute you for being with us and bringing your particular case histories so that they can be a part of the permanent record of our Aging Committee.

I read some of the testimony on the plane and even knowing the stories in advance, it is sort of emotionally draining to hear the stories of the Kaisengers and Mr. Gibbons and even Mr. Keane from the people themselves. It is always something that is hard to deal with emotionally.

I am going to ask a question of the Kaisengers and Mr. Gibbons as well. Maybe New York is different from Pennsylvania. Is there a need here to "spend down" all your assets including your home before you would be entitled to Medicaid in these instances?

Ms. KAISENGER. I think from what we were told that that is very likely that our home would be jeopardized. I didn't believe it when I heard it at first; it just can't be true, you know. From everything else that I am hearing, for anything else to be able to kick in for us, we would have to be financially drained.

Mr. BORSKI. Mr. Gibbons, is that your case?

Mr. GIBBONS. I heard that effective October 1st, before Medicaid would take care of nursing home situations, we would have to "spend down" to an asset base of \$60,000, and then Medicaid would kick in. Well, \$60,000 isn't very much.

Mr. MANTON. That includes all assets, including the equity in the home?

Mr. GIBBONS. That is what I understand.

Mr. MANTON. In today's prices, that is not a lot—

Mr. GIBBONS. That is correct.

Mr. MANTON. —in terms of home equity.

Mr. KEANE. If I might add, the situation has gotten better. I know when I was taking care of my aunt, we had to spend down literally to then what was a \$1,500 funeral expense, and that included the house and all the assets. Today, with the new spousal and impoverishment protection in Pennsylvania, if the spouse is still living in the home, the home will be excluded, and then there is that other \$60,000 or so. It is a little better but it still not addressing the problem comprehensively.

Mr. MANTON. Even though the home is excluded from the spend down, is there a lien created which would perhaps have to be satisfied later if the house were disposed of?

Ms. PERA. No.

Mr. MANTON. Mr. Chairman, thank you very much.

Mr. BORSKI. Thank you, Congressman Manton.

Let me again thank our panel for coming by today. I greatly appreciate it and I know it was very difficult to do.

As I was reading the testimony it brought a tear to my eye and then here you folks come to deliver it. I think it will move all Americans to understand the problems and give us all a push to

move to solve them. Again, thank you very, very much for sharing your stories with us.

The committee will take a brief break at this point and reconvene in a few moments.

[A brief recess was taken.]

Mr. BORSKI. Ladies and gentlemen, will you please take your seats. The subcommittee will reconvene and I would like to welcome our next panel.

Ms. Linda Hahn, Director, Older Adult Services of Family Service of Philadelphia and Co-chair of CARIE [Coalition of Advocates for the Rights of the Infirm Elderly] Caregiver Assistance Service, will discuss caregiving issues.

Ms. Betty Stagg, Director of Product Development, Independence Blue Cross, will discuss the development of long-term care insurance and the problems in establishing both comprehensive and actuarially-sound policies.

Mr. Frank Podietz, Director of Operations, Philadelphia Geriatric Center, will describe the ongoing research into long-term care needs at the PGC.

Mr. Rodney Williams, Executive Director, Philadelphia Corporation for Aging, will explain PCA's efforts in delivery and referral of long-term care services.

Ms. Hahn?

PANEL TWO—CONSISTING OF LINDA HAHN, DIRECTOR, OLDER ADULTS SERVICE OF FAMILY SERVICE OF PHILADELPHIA; BETTY M. STAGG, DIRECTOR, PRODUCT DEVELOPMENT FOR THE AGING, INDEPENDENCE BLUE CROSS; FRANK PODIETZ, M.B.A., DIRECTOR OF OPERATIONS, PHILADELPHIA GERIATRIC CENTER; AND RODNEY D. WILLIAMS, EXECUTIVE DIRECTOR, PHILADELPHIA CORPORATION ON AGING

STATEMENT OF LINDA HAHN

Ms. HAHN. Good morning, Congressman Borski, Congressman Manton. Thank you so much for the opportunity and honor of presenting testimony to you today on behalf of Philadelphia's caregiving families. I am Linda Hahn, Director of the Older Adults Service of Family Service of Philadelphia. With funding from the United Way of Southeastern Pennsylvania and from the Philadelphia Corporation for Aging, Family Service is able to offer counseling services to older adults and their caregiving families. Since 1983, this specialized service under my direction has been involved with approximately 1000 caregivers of the infirm elderly.

Two years ago I joined the Caregiver Coalition and now am its co-chair. The Caregiver Coalition, sponsored by the Coalition of Advocates for the Rights of the Infirm Elderly, known as CARIE, is made up of individuals and organizations working to improve the well being of caregivers of dependent elderly persons. The Caregiver Coalition works to educate legislators, service providers, business persons and the general public about the needs of caregivers, and to advocate for policies and programs that will address these needs.

My joining the coalition came as a result of assessing the needs of our large caseload of caregivers, that is, family members who

are caring for older relatives who may or may not live with them. I realized over time that psychological support, family counseling and the teaching of stress management techniques were very useful to these caregivers; but without more formal supports, such as more available homemaker services, adult day care services and other respite arrangements, many families eventually break down under the added stresses of caregiving. I think we saw that in the first panel quite vividly. Few of us are trained to bathe a grown adult, diaper them, keep track of dozens of medications or deal effectively with them when minds are beginning to fail. We just don't have preparations for those kinds of roles.

Although you have heard some very moving stories this morning, I feel compelled to talk to you about a few families from our case load. Mrs. L is a 75-year-old caregiver for her husband of 50 years. Eighty-year-old Mr. L suffers from Parkinson's disease, mild aphasia from a recent stroke and considerable depression. They live in a Northeast Philadelphia row home which has many steps, a classic architectural nightmare of Philadelphia for families who have immobile family members

Mrs. L cannot get her husband down the steps to go outside for some fresh air. His bed is in the dining room and he uses a bedside commode to reduce the trips up and down the stairs. Even though they have one of those elevators that goes up and down, he is really quite fearful of being put in it and strapped in it. It is hard for her to get him in it because he is so heavy.

Mr. BORSKI. Excuse me. You mean the chair?

Ms. HAHN. Yes. It goes up on kind of a pulley. There is sort of a track that goes up the stairs.

If she needs to transport him to a doctor, due to complications in Pennsylvania's share-a-ride system, she cannot always be assured that there will be two persons on a van. I almost made the mistake of saying two men, but I will say, two persons. Really, quite frankly, it does take two men to carry a patient and a wheelchair down the concrete steps of a Philadelphia home. She can't always be assured that she will get the right kind of transportation service.

Since Mr. L is unsteady on his feet because of the Parkinson's disease, Mrs. L lies awake all night in order to help him to the commode. She is afraid that he will fall again. She lies on the sofa in the living room because, if she sleeps upstairs, she might not hear him. His bladder keeps them both up all night.

She is exhausted from the lack of sleep. Although they have had an exemplary marriage, 50 years, she is beginning to feel he falls on purpose for attention. She is getting angry and does not know how much more she can take.

You might be thinking, are there children, grown, middle-aged children? Mr. and Mrs. L, have in fact done a fine job of raising one son who is now happily employed out of State. He has many commitments to his growing family. Consequently, her son is of little help with hands-on caregiving.

Quite frankly, how many of us who have had the privilege of being happily employed and having our own families—and because of the demographics of the American society which has perhaps given us opportunities for employment outside of our hometown—

how many of would go back and how often? How many of us would move back to handle the situation with our aging parents?

One way of helping Mrs. L with her caregiving might be to hire a night nurse. Another help might be to purchase temporary respite care, in a nursing home, so that she could perhaps go visit her son to get refueled. These resources are out of their price range. We are talking about, as Congressman Manton said, a lower middle income community of Philadelphia; it is probably similar to Queens.

If Mrs. L becomes ill as many caregivers do, or reaches the point where she can no longer take the stress of caring for her husband at home, costly nursing home care is an option. Actually, to tell the truth, I don't think for her it would ever be an option. I just can't see her ever doing this. She was surprised to learn, and I was there when she learned it, that neither Medicare nor their private insurance covers this long-term care option.

A nursing home, at the very minimum, would be \$24,000 a year. Their son is not a potential source of financial help. He is facing a large mortgage and his children's college tuition. When Mr. and Mrs. L are broke, as you know, the State will pay their long-term care bill, until the end of their lives. The State will not help pay the long-term care bill for Mr. L's care at home except through some very specialized programs in Philadelphia demonstration projects, which exist in some counties and neighborhoods, but not in others.

And, if I might, another family. Mrs. M just finished raising three children. After the last one married, Mrs. M settled back into a full-time work routine as a private secretary. Her husband was delighted because her added income could help pay for the retirement that they had planned, which included travel in their recreational vehicle and winters in Florida. Six months later Mrs. M's father suffered a stroke, very suddenly. He had been a healthy, strapping guy. A stroke comes along very fast. It left him paralyzed. Her mother, ill herself with diabetes and severe arthritis, had to place the father in a nursing home. She no longer could care for him. The problem was, he was no longer there to care for her.

Mrs. M, who was the middle-aged person I have referred to, could not handle operating two households. She had to move her mother in with her and her family. Mrs. M continues to visit her father three times a week, in a local nursing home, in the Northeast area of Philadelphia. She also attends to her mother's daily needs, which includes getting her dressed in the morning. Mrs. M is always late for work and is exhausted because the homemaker is often late or doesn't show up. Her boss is understanding but for how long? His typing is backlogged.

Like 35 percent of all female caregivers, Mrs. M adjusted her work schedule to suit her mother's caregiving needs. Her mother is unhappy in their home. It is a myth—older people do want to live with their children. If you asked for a show of hands, most would say they do not want to do that. The mother misses her privacy and so does Mrs. M's husband. He, although he has a good relationship with his mother-in-law, said this was not particularly his

choice. The children are now out of the home and he looked forward to the privacy with his wife.

This family lives in a section of Philadelphia that allows them to be eligible for some matching funds for respite care, but, only if mother continues to live in that home. That really is a resolution that this family is not happy with.

With adequate in-home services like a homemaker or home health aide, Mrs. M's mother could still remain in her home. But, people in their income bracket cannot afford to supplement the few hours of free weekly care that the county can provide. Ten dollars a hour, every day, for years to come, adds up. This kind of long-term care is expensive. It isn't covered by Medicaid, Medicare, private insurance or anyone else. As a matter of fact, as the chart shows, only about 1 percent of long-term care nationally is covered by private insurance.

The Area Agency on Aging cannot begin to fill the need for in-home services when, over the past 5 years, there have been as many as 1,500 people on the waiting list for those services. And, I have to tell you, as a social worker who sees these people and realizes that that is the service that will most likely keep a family intact, it is about a 1-year wait. It is very hard to walk out of a house and to close the door behind me, I have to tell you, knowing that family won't get the help it needs.

Eventually Mrs. M may have to quit her job. About 11 percent of all female caregivers eventually quit their jobs to stay home and care for either their husbands or parents.

Mr. M, her husband, the son-in-law, will have to postpone retirement out of financial necessity. She will have no retirement pension because she hasn't worked long enough or consistently enough to earn it. Her productivity at work clearly will be effected as well. Her work is affected directly, by the need to make numerous caregiver-related phone calls on the job or to go to the doctor or the Social Security office which is only open during the day. She also has to take time off to recover from the exhaustion and stress that are frequent byproducts of caregiving.

The problem of home aides being late or not showing up is really the most frequent complaint of employed caregivers as well as older spousal caregivers, who are unable to handle the caregiving task alone. I was in a home a couple of days ago here in Northeast and the homemaker had not shown up that day, and the elderly couple could not figure out how they were going to empty the commode. No one could lift the bucket.

The problem I think—and, I don't want to do a job on the home health industry—one of the problems has to be that the kinds of aides that are hired are hired at very, very low wages because families can't afford to pay exorbitant hourly rates. There is a whole level of quality of care pushed down. You are getting people who are just not being paid a wage that makes them really want to go in to work. Of course, imagine the stress of somebody trying to get off to their job and the homemaker doesn't come to take care of mother.

In recent years, research has repeatedly demonstrated that most families do not abandon their older relatives. Families are general-

ly in close contact with their older members and provide 80 percent of the home care when needed, or when older people are ill or frail.

The 1987 AARP random sample survey of U.S. households found that 7.8 percent of households had a caregiver. For this survey a caregiver was defined as a person who provided unpaid assistance with at least two activities of daily living, that is transportation, shopping, managing finances, or one personal care activity of daily living, such as bathing, dressing, eating, toileting, that sort of thing, to a person 50 or older within 12 months of the time of the interview. That translated into 7 million households in America with a caregiver. About half of the respondents were actively caregiving at the time of the interview. Applying this estimate to Philadelphia, there are over 50,000 households where someone during the past year has been a caregiver for a person 50 years old or older.

The large majority of caregivers are spouses or adult daughters of an impaired older person. Most caregivers are women. The average age of caregivers ranges from 45 to 57 years, depending upon which survey you look at, with 15 to 35 percent being older people themselves. Usually there is only one caregiver, the primary caregiver, who shoulders most of the burden by him or herself.

Most caregiver research estimates that about 75 percent of caregivers live with the impaired older person, although other studies found that 37 percent of households were shared by both the caregiver and the impaired person. Actually in terms of stress, it is hard to estimate what's harder, to live with the impaired person or to live in a situation where you have to go a couple of times a week and make the visit and do the hands-on care.

Caregivers demonstrate a high degree of commitment to their role. I think we saw this this morning very vividly. About one quarter of caregivers spend 8 hours a week, one quarter, 9 to 20 hours a week. One quarter of caregivers spend 21 hours or more a week, and about 11 percent of caregivers give constant care. I think that Timmy's parents are an example of that. One fourth of caregivers had been providing care for less than 1 year, half for 1 to 5 years, and one fourth for 6 years or more. One fourth of all caregivers studied had been doing this job for 6 or more years of their life.

While caring for an elderly relative can be a positive and gratifying experience, it takes its toll over the long haul. Caregiving creates social, psychological, physical and financial problems which can have a major impact both on family and society. Caregiving can disrupt family and social life, cause work conflicts and drain or deplete finances.

Many caregivers are women who are "sandwiched" between child and elder care, often with the responsibility of a paying job as well. I think the demographics of the American society will show that that population will continue to grow as more women are in the workplace. Balancing the demands of caregiving and work obligations can create stress and any number of work-related problems.

An interesting study was done by Travelers Insurance which showed increased absenteeism and unscheduled days off, excessive use of the phone, tardiness, use of vacation and personal leave for

caregiving responsibilities, and ultimately, premature loss of long-term employees from the workforce.

For those caregivers who are unable to work full-time in the paid labor force due to caregiving responsibilities, the scenario is bleaker. These individuals, usually women, have reduced salaries, benefits and retirement income. The 1982 National Long-Term Care Survey estimated that at least one third of caregivers were poor or near poor, or will become poor, it looks like.

The physical and emotional strains of caregiving over an extended period of time can create health problems. It is not uncommon for caregivers to neglect their own health needs while older infirm persons are in their care. And, I hear that all the time from caregivers, they unfortunately, become dependent patients. "If you continue to give me a hard time, I am going to get sick and die before you." I can't tell you how many situations I have seen where out of the frustration that kind of thing begins to happen.

But, it is true, it is true. Research shows a high correlation between psychosomatic illness such as respiratory problems and gastrointestinal problems, and caregiving responsibilities.

Of course, the emotional problems that the caregivers experience are in the area of frustration, guilt, insomnia, headaches, irritability, and anxiety. Guilt—I could give you a whole story about guilt. No matter how much somebody loves that family member and no matter how much care they provide, they still feel guilty, they still feel that they are not doing enough. There is a lot of interesting psychological research about why that occurs.

Many caregivers cite problems in the physical environment such as the lack of private space or difficulty transporting the impaired person, which interfere with caregiving. Most that I visit in the homes have the hospital bed downstairs so the entire family lives in an arena of illness and sickness. It affects all generations in a family.

Let me speak briefly to some of the barriers to getting better service, barriers to resources. And, if I could, I have some recommendations. I don't know if they are so creative that they are some that you haven't thought up. But, I would like to take the opportunity.

Given the high demands of caregiving and the evidence of detrimental stress on the caregiver, one would expect more use of formal services than we have actually found. Families still tend to do most of the caregiving as opposed to formal institutional caregivers.

Barriers in the services that deter their use by caregivers are: the lack of third party reimbursement to help finance the costs of services. I work with so many caregivers that are afraid to buy in-home care because they don't know what is down the line. So, you see older people sitting there with a budget figuring out, "How much can I give?" to this because of what is going to be down the line and they are afraid of what's going to happen to their own care.

Family caregivers are often unaware of available services. They become very isolated. They stay in the house and they begin to lose relationships and find that they don't know what's going on. By

the time that I get in there I am appalled by how little they know about what they really deserve.

Long-term care services are not designed for convenient use by family caregivers who are working. For instance, adult care day centers can't keep a person beyond 3 o'clock in the afternoon. This does not particularly help the employed caregiver. Many family members are too overwhelmed with caregiving to understand and negotiate the complex maze of services which may be available to them.

The lack of third party reimbursement—I think we have already talked about that, particularly Medicare and Medicaid. The custodial and respite services most often requested by caregivers is the most intractable obstacle to using services.

Federal reimbursement programs even discriminate against the caregiver. For example, Social Security income payments are reduced by one third if the elderly recipient is living in the home of another individual or family member. Medicare covers only intermittent home care. It can happen, if a family pays for care in between the care that they get through Medicare, which, of course, is medical care in the home, if they buy any other kinds of benefits themselves, they actually later on may not be eligible for full Medicare benefits because they no longer are deemed as an intermittent acute care case, they are now long-term care recipients. How many people would know that?

The Tax Reform Act of 1986 requires a caregiver to show expenses that are 7.5 percent of gross income before a dependent care benefit can be taken—this level was increased from 5 percent in previous years. As you know, Medicaid only pays for institutional care, and only when the individual has depleted all assets. Another obstacle is that aging services are designed to address the needs of the impaired person, without consciously incorporating the needs of the caregiving family. As I said, adult day care centers are not open long enough, or they lack adequate transportation to make them a useful service option for the employed caregivers.

Another example is the home care worker who is not trained to work with cognitively or behaviorally impaired people. Often family caregivers feel that they have to stay home even though the homemaker is there because they are very fearful of the level of care. And, I have seen that. I will go in and say, "Why don't you go out and take a walk while the employed health caregiver is there, the home health aide?" I can't get these people out of the house because they are really afraid that something is going to happen to their loved one, so they are there anyway.

In fact, public funding of home care programs often targets older people living alone, so in fact, it is not helpful to caregivers. Philadelphia in-home services, funded by the Older Americans Act and the State Lottery, are always stretched beyond capacity, often causing even frail older people living alone to be on a waiting list for needed services as I said before.

Recommendations. I would like to see you expand Federal funding for respite services in two main areas; in-home health care such as home-making services, and adult day care centers so that they more adequately meet the needs of the employed caregiver.

Transportation has to be guaranteed. Doctors available on site.

We need to increase the funding under Title III, The Older American Act which would significantly reduce the wait for chore services, home-delivered meals, and homemaker services, and we would not discriminate against households where there is actually a caregiver. It is so hard as a social worker to prioritize who is in more need, the caregiving employed family which perhaps is most often the middle-class family like we have seen this morning, or families that are of themselves in chaos where the older person is living alone and there aren't adequate family caregivers. How do you make decisions like that?

Make Medicare less restrictive and more inclusive—for example Medicare could cover the costs of adult day care.

Expand support groups and education for family caregivers by providing block grants and other Federal monies for such services. Families hit with the sudden illness of a member had no preparation and they begin to feel alone and isolated with their problem.

Resources need to be advertised and easily accessible. As was said this morning the number of persons 65 and over needing help with activities of daily living is growing. Five million were reported in 1984. In 1990, an estimated 6.2 million will need help with at least one activity of daily living. And by 2030, 13.8 million people in America will need this kind of care.

We need to provide incentives to industry to offer benefits which assist employed caregivers. Almost 35 percent of employed caregiving husbands worked fewer hours in order to perform caregiving tasks. I think that what is going to happen is that as more women—this is speculation—as more women are employed, employed men are going to have to get into the scene, because men are not going to be able to count on their wives to take care of their parents. If your sister is employed and your wife is employed, I think you are going to have to think about this if you are a man.

Enact the Family Medical Leave Act. To force companies to support the growing caregiving demands of all of their employees, thus reducing the added stresses of fear and eventual loss of the job for poor performance evaluation because you have been absent from time to time.

Reexamine tax allowances for caregivers. Now this is not my field of expertise. But, when I realized what the floor was in terms of what percent of gross had to go to caregiving needs, and that that was changed with the Tax Reform Act, I thought it was certainly discriminatory against caregivers.

Also, to be eligible for the dependent care credit, the dependent must live with the caregiver. According to my statistics, that is not reflective of American reality, where one quarter of the infirm elderly do not live with the caregiver. But that still does not mean that a lot of time is not spent by a caregiver taking care of that patient.

Another requirement to get a tax credit, as far as I understand it, is that all caregivers in the home must be employed. Statistics show that one third to one half of all caregivers actually are not employed.

We need to enact legislation calling for higher standards for the training, screening and testing of the in-home companions and

home health aides. The high turnover rate is an obvious source of frustration for the dependents and their families.

We need to reexamine laws and policies that may be disincentives to families to provide care to older relatives. As I mentioned, the Supplemental Security Income program that requires where a family member will live, stipulates it has to be outside of the home. And another problem to look at is Medicare's denial of intermittent home care benefits because family members have been able to pay for some intermittent care themselves.

We need to investigate and implement financial strategies that support family caregiving which might include—might include—a direct payment to family caregivers when their care prevents or reduces the need for formal or institutional care. This is particularly useful strategy, I think, for low-income families who are not going to benefit from tax reforms.

Augmenting the income lost from absence in the workplace due to caregiving, and perhaps vouchers allowing families flexibility to purchase services when and how they need them, that would fit their particular needs.

And I guess, being mindful, and I know you are, but I need to say it that the catastrophic program passed by Congress and now in its restructuring, shall we call it, phase has had little impact on the long-term custodial needs of the families that I am representing.

I am not a caregiver yet. Chances are that I will be. I certainly identify with the "sandwiched" generation of the employed caregiver. I have parents who live in Philadelphia. My brothers have split. It is going to be up to me. They have good jobs outside of this community, thank you. The demographics are clear. The problems posed by our aging society demand the legislature's immediate and humane attention to immediate and long-term care.

Again, my gratitude for your time and your genuine caring for American's families.

[The prepared statement of Ms. Hahn follows:]

Testimony at Hearing of the House Select Committee on Aging
 Subcommittee on Health and Long-Term Care
 "Long-Term Care: the Critical Need"

"CAREGIVING ISSUES"
 by
 CARIE's Caregiver Coalition

September 15, 1989

I am Linda Hahn, Director of the Older Adults Service of Family Service of Philadelphia. With funding from the United Way and PCA, Family Service is able to offer counseling to older adults and their caregiving families. Since 1983, this specialized service under my direction has been involved with over 1000 caregivers of the infirm elderly.

The Caregiver Coalition

Two years ago I joined the Caregiver Coalition and now am its co-chair. The Caregiver Coalition, sponsored by the Coalition of Advocates for the Rights of the Infirm Elderly (CARIE), is made up of individuals and organizations working to improve the well-being of caregivers of dependent elderly persons. The Caregiver Coalition works to educate legislators, service providers, business persons and the general public about the needs of caregivers, and advocates for policies and programs that will address these needs.

My joining the Coalition came as a result of assessing the needs of our large caseload of caregivers, ie. family members who are caring for an older relative who may or may not live with them. I realized that psychological support, family counseling and the teaching of stress management techniques were very useful to these caregivers; but without more formal supports, such as homemaker services, adult day care and other respite arrangements, many families eventually break down under the added stressors of caregiving. Few of us are trained to bathe a grown adult, diaper them, keep track of dozens of medications or deal effectively with them when their minds are failing.

Caregivers I Have Known

Mrs. L is a 75 year old caregiver for her husband of 50 years. 80 year old Mr. L suffers from Parkinson's Disease, mild aphasia from a recent stroke and considerable depression. They live in a Northeast Philadelphia row home which has many steps... a classic architectural feature of Philadelphia's homes which becomes a nightmare for many of our older residents. Mrs. L cannot get her husband down the steps to go outside for some fresh air. His bed is in the dining room and he uses a bedside commode to reduce trips up and down the stairs.

Since Mr. L is unsteady on his feet because of the Parkinson's, Mrs. L lies awake all night in order to help him to the commode. She is afraid that he will fall again. She lies on the sofa in the living room because, if she sleeps upstairs, she might not hear him. His bladder keeps them both up all night.

Mrs. L is exhausted from the lack of sleep. Although they have had an exemplary marriage, she is beginning to feel he falls on purpose for attention. She is getting angry and does not know how much more she can take.

Are there children to help, you ask? Mr. and Mrs. L have done a fine job raising one son who is now happily employed...out of state...and has the many commitments of a growing family. Consequently, her son is of little help with caregiving.

One way to help Mrs. L with her caregiving might be to hire a night nurse. Another help might be to purchase temporary respice care for Mr. L while Mrs. L visits her son and gets refueled. But these resources are out of their price range.

If Mrs. L becomes ill, as many caregivers do, or reaches the point where she can no longer take the stress of caring for her husband at home, costly nursing home care is an option. Mrs. L was surprised to learn that neither Medicare nor their private insurance covers this long term care option which costs at least \$24,000 a year. Their son is not a potential source of financial help because he is facing a large mortgage and his childrens' college tuition. When Mr. and Mrs. L are broke, the State will pay the long term care bill until the end of their lives.

Mrs. M just finished raising three children. After the last one married, Mrs. M settled back into a full-time work routine as a private secretary. Her husband was delighted because her added income could help pay for the retirement they had planned, which included travel and maybe winters in Florida. Six months later, Mrs. M's father suffered a stroke which left him paralyzed and aphasic. Her mother, ill herself with diabetes and severe arthritis, had to place Dad in a nursing home and no longer had his help for her daily care. To reduce operating two households, Mrs. M moved Mom into her home.

Mrs. M continues to visit her father three times a week in the nursing home and also tends to her mother's daily needs, including getting her dressed in the morning. Mrs. M is always late for work and exhausted. Her boss is understanding, but for how long? His typing is backlogged. Like 35% of all female caregivers, Mrs. M adjusts her work schedule to suit her mother's caregiving demands. Her mother is unhappy in their home. She misses her privacy and so does Mrs. M's husband.

With adequate in-home services like a homemaker or home health aid, Mrs. M's mother could still remain at home. But people in their income bracket cannot afford to supplement the few hours of free, weekly care their county provides. Ten dollars an hour everyday for years to come adds up! This kind of long term care expense isn't covered by Medicaid, Medicare, private insurance or anyone else. The Area Agency on Aging cannot begin to fill the need for in-home services where, over the past five years, there have been as many as 1500 people waiting for an in-home service.

Eventually Mrs. M may be forced to quit her job, as 11% of all caregivers do, and Mr. M will have to postpone retirement out of

financial necessity. Mrs. M will have no retirement pension because she wouldn't have worked long enough to earn it. While Mrs. M continues to work and care for her parents, her productivity at work is affected. Her work is affected both directly, by the need to make numerous caregiver-related phone calls on the job or to go to the doctor or the social security office which is only open during the day, and indirectly by exhaustion and stress that are frequent byproducts of caregiving. Who can begin to calculate the costs of the marital stress and the smashed dreams? These costs could be avoided if adequate and affordable long term care options were available.

A National Profile of Caregivers

In recent years research has repeatedly demonstrated that most families DO NOT abandon their older relatives. Families are, generally, in close contact with their older members and provide 80% of the home care needed when older people become ill or frail.

The 1987 AARP random sample survey of U.S. households found 7.8% of households had a caregiver. For this survey a caregiver was defined as a person who provided unpaid assistance, with at least 2 instrumental activities of daily living (transportation, shopping, managing finances, etc.) or one activity of daily living (bathing, dressing, eating, toileting, etc.) to a person 50 or older within 12 months of the time of the interview. This survey finding translates to about 7 million households with a caregiver. About half of the respondents were actively caregiving at the time of the interview. Applying this estimate to Philadelphia, there are over 50,000 households where someone has, during the past year, been a caregiver for a person 50 years and older.

The large majority of caregivers are spouses or adult daughters of an impaired older person. Most caregivers are women. The average age of caregivers ranges from 45 to 57 years (depending upon which survey you look at) with 15% to 35% being older people themselves. Usually there is only one caregiver, the primary caregiver, who shoulders most or all of the burden. Most caregiver research estimates about 75% of caregivers live with the impaired older person, although the AARP survey found only 37% of households were shared by both caregiver and impaired older person.

Caregivers demonstrate a high degree of commitment to their role. The 1982 National Long-Term Care Survey found that most caregivers spent an average of four hours every day doing caregiving tasks such as assisting with personal care, mobility, homemaking and finances. According to the 1987 AARP survey, the following amount of time is spent on caregiving:

- about 1/4 of caregivers spend 8 hours or less per week,
- about 1/4 of caregivers spend 9-20 hours per week,
- about 1/4 of caregivers spend 21+ hours per week (but not constant care), and
- about 11% of caregivers give constant care.

One fourth of the caregivers had been providing care for less than one year, half for one to five years and one fourth for 6 years or more. Nearly all caregivers expect to continue providing care for as long as needed.

Impact of Caregiving on the Family

While caring for an elderly relative can be a positive and gratifying experience, it takes its toll over the long haul. Caregiving creates social, psychological, physical and financial problems which can have a major impact both on family and society. Caregiving can disrupt family and social life, cause work conflicts and drain or deplete finances.

Many caregivers are women who are "sandwiched" between child and elder care, often with the responsibility of a paying job as well. The 1987 AARP survey found 55% of caregivers were employed outside of the home. Balancing the demands of caregiving situations and work obligations can create stress for the employed person, causing any number of work-related problems, such as increased absenteeism and unscheduled days off, excessive use of the phone, tardiness, use of vacation and personal leave for caregiving responsibilities, and ultimately, premature loss of long term employees from the work force.

For those caregivers who are unable to work full-time in the paid labor force due to caregiving responsibilities, the scenario is bleaker. These individuals, usually women, have reduced salaries, benefits and retirement incomes. The 1982 National Long-Term Care Survey estimated that at least one third of caregivers were poor or near poor.

The physical and emotional strains of caregiving over an extended period of time can create health problems. It is not uncommon for caregivers to neglect their own health needs while older infirm persons are in their care. Also, caregivers frequently strain themselves while performing physical tasks of caregiving such as lifting and turning a disabled adult.

Emotional strain has been cited by numerous studies as one of the most widespread negative effects of caregiving. Many caregivers experience frustration, guilt, insomnia, headaches, irritability, and anxiety. Severe depression is much more common among caregivers than among age-matched peers. These symptoms may result in disrupted home and work routines, difficulty setting priorities, and use of medication or alcohol as a way of coping with the strains of caregiving.

Many caregivers cite problems in the physical home environment, such as the lack of private space or difficulty transporting the impaired person, which interfere with caregiving. Modification of the home environment can ease daily care of the older person and be a valuable service to the caregiver.

Barriers to the Use of Formal Services

Given the high demands of caregiving and the evidence of detrimental stress on the caregiver, one would expect more use of formal services than has been found. Barriers in the service system that deter its use by caregivers are:

- the lack of third party reimbursement to help finance the costs of services,
- family caregivers are often unaware of available services,

- long term care services are not designed for convenient use by family caregivers who are working, and
- many family members are too overwhelmed with caregiving to understand and negotiate the complex maze of services which may be available to them.

The lack of third party reimbursement, particularly Medicare and Medicaid, for the custodial and respite services most often requested by caregivers is the most intractable obstacle to using services. Federal reimbursement programs even discriminate against the caregiver. For example, Supplemental Security Income (SSI) payments are reduced by 1/3 if the elderly recipient is living in the home of another individual or family member. Medicare covers only intermittent home care but, if family pays for additional home care, Medicare may deem that home care is NOT intermittent and deny all home care benefits. The Tax Reform Act of 1986 requires a caregiver to show expenses that are 7.5% of gross income before a Dependent Care benefit can be taken - this level was increased from 5% in previous years.

Another obstacle is that aging services are designed to address the needs of the impaired older person, without consciously incorporating the needs of the caregiving family. For example, many adult day care programs are not open long enough each day or lack adequate transportation to make them a useful service option for the caregiver who works. Another example is the home care worker who has not been trained to work with cognitively or behaviorally impaired people, thus requiring the family caregiver's presence while the worker is on duty. In fact, public funding of home care programs often targets older people living alone, in essence discriminating against frail older people with caregiving families. In Philadelphia, in-home services, funded by the Older Americans Act and the State Lottery, are always stretched beyond capacity, often causing even frail older people living alone to be put on a waiting list for needed services.

Local Philadelphia Services to Support Family Caregiving

Respite care is the service most often described by families when asked what would help them in their caregiving role. Families say they could continue to provide essential care if they knew they would be able to get a temporary break from caregiving. Rather than being one specific service, respite care is a way of structuring and packaging services to correspond to the individual needs of family caregivers for occasional relief. The most common services used as respite are in-home care provided by a companion or home health aide, adult day care, or a brief stay in an institution such as a nursing home or hospital.

In Philadelphia there are several projects, with temporary funding, aimed at bringing respite services to caregivers. PCA is one of the demonstration sites for the State's Family Caregiver Support Project (FCSP). This Project provides case management, caregiver education, benefits counseling, and financial assistance in purchasing respite care and other supportive services. The concept of caregiver support is expanded to include helping caregivers pay for adaptive equipment and home modifications that would ease caregiving. In Philadelphia, this Project serves about 300 families a year and has,

without doing any publicity about its services, another 300 families on its waiting list for service.

The Counseling for Caregivers Program at the Philadelphia Geriatric Center is a small, grant-funded project which can provide family caregivers with case management, counseling and limited financial help to purchase respite services. Catholic Social Services also has a special, grant-funded project which offers limited financial assistance for respite to a small number of family caregivers.

While these three "respite" projects provide valuable services to family caregivers, each project serves a very small portion of the 50,000 caregiving households which we estimate to exist in Philadelphia. Also, each project has only temporary funding.

Employee assistance for caregivers is the focus of several programs in Philadelphia, such as those sponsored by CARIE and the Philadelphia Center for Older People. These programs are working with corporations to provide employee benefits to assist with caring for an older relative. Services which corporations may purchase from caregiver employee assistance programs are educational sessions for employees and individual telephone counseling for caregiver employees. In addition to specialized programs for caregiver employee assistance, some existing employee assistance programs (EAPs) are adding "caregiver needs" to the list of employee problems to which they can respond.

Long term care insurance coverage is becoming a more available option for older people and their families. At this time, however, significant limitations exist in many policies that make them less than comprehensive. In Pennsylvania, state legislation has been introduced to define the parameters of long term care insurance and protect families from insurance fraud.

Caregiver groups for education and support are fostered by many aging service agencies, such as Family Service of Philadelphia, and by grassroots caregiver organizations such as the Philadelphia Chapter of the Alzheimer's Disease Association and Children of Aging Parents. CARIE's Caregiver Coalition is an advocacy group for caregivers, with representatives from caregiver support groups and agencies serving with caregivers of frail elderly, working for improved supportive services for family caregivers.

Training professionals to work with family caregivers has been the focus of a number of recent conferences, training seminars and educational publications.

The array of caregiver support services are primarily demonstration projects or limited programs. Few have been adequately evaluated. Effective ways of helping family caregivers need to be determined and this knowledge integrated into existing aging services as well as being used to create specialized caregiver services. Caregiver advocates support long term care policy and practice which fosters partnerships among public programs, private industry and families to meet the long term care needs of our older population.

Recommendations for Federal Support of Family Caregivers

1. Expand funding for respite care services in two main areas:
 - a. in-home health care, such as homemaking services, and
 - b. adult day care.
2. Increase funding under Title III of the Older Americans Act.
3. Make Medicare less restrictive and more inclusive, for example Medicare could cover the costs of adult day care.
4. Expand support groups and education for family caregivers by providing block grants and other federal monies for such services.
5. Provide incentives to industry to offer benefits which assist employed caregivers.
6. Enact the Family Medical Leave bill.
7. Re-examine tax allowances for caregivers.
8. Enact legislation calling for higher standards for the training, screening and testing of in-home companions and home health aides.
9. Re-examine laws and policies which may be disincentives to families to provide care to older relatives, Medicare's denial of intermittent home care because a family member has paid to continue this care.
10. Investigate and implement financial strategies that support family caregiving which might include:
 - a. direct payment to family caregivers when that care prevents or reduces the need for formal or institutional care,
 - b. augmenting the income lost from absense in the work place due to caregiving, and
 - c. vouchers allowing families flexibility to purchase services when needed.

Mr. BORSKI. Ms. Stagg.

STATEMENT OF BETTY M. STAGG

Ms. STAGG. Congressman Borski, Congressman Manton, good morning. My name is Betty Stagg. I am the Director of Product Development for the Aging, Independence Blue Cross. Independence Blue Cross was founded in 1938 and we provide health insurance and other related services to over 2 million subscribers here in southeastern Pennsylvania.

I would like to cover the highlights of my testimony and would ask that my entire testimony be submitted for the record.

Mr. BORSKI. Without any objection, it is so ordered.

Ms. STAGG. Thank you. I am pleased to have the opportunity to appear before you. I will testify on the development of private long-term care health insurance which has been mentioned today but not in detail. I will comment on the importance of financing, in paying for this complex and costly need, and the current status of long-term care insurance on the market today.

As requested, I will try to touch on the challenges that insurance companies face in establishing actuarially sound long-term care policies.

I think that it is obvious that there has been a broad recognition of the importance of long-term care and how to pay for it as a national issue. It is already an enormous cost and will be even be a larger one when the baby boom generation retires in the next century. The nursing home bill alone, I think, is over \$38 billion now, and about half of that, as your charts show, is paid out-of-pocket. Most of the other half is already paid by the government.

I would like to talk about the status of the long-term insurance market because it was alluded to today. The availability of this insurance has increased a great deal over the past few years. A recent survey by the Health Insurance Association of America indicates that 1.1 million policies had been sold as of the end of 1988, and that was up from just a few policies around the beginning of this decade. The number of insurance companies offering long-term care had also increased, from about 16 in 1984 to 105 at the end of 1988. In addition, there are 19 additional Blue Cross/Blue Shield plans offering long-term care insurance in their service areas.

I would like to touch briefly on what these policies cover. Long-term care insurance is a very new line of personal insurance. It is sold primarily to individuals between the ages of 50 and 80. These policies usually pay for all levels of care in a nursing home. They may also pay for skilled and nonskilled care in the home. They are beginning to pay for things like homemakers, personal care aides, adult day care centers and, in some cases, respite care, and case management.

The policies pay a fixed amount per day. They may pay actual charges but it is up to a limit and the purchaser chooses that daily benefit amount when he or she buys the policies. It may be \$50, or \$75, or \$100 per day that it will pay. The policy has a duration of coverage. They will last 2, 4 or 6 years and sometimes longer depending on what the purchaser chose when he or she bought the policy. Increasingly, policies are offering an option of a periodic in-

crease for the benefit so it helps the policy to keep pace with the rising cost of the care that is usually offered for additional premium, however.

All long-term care policies contain some restrictions, some exclusions and some limitations which I will touch on further in a moment. All policies on the market today evaluate the individual's health status to determine whether they can buy the policy.

Policies are based on the age of the buyer at the time of the purchase. They are less expensive if they are bought at younger ages. Most of them are guaranteed renewable and that is what they should be, guaranteed renewable.

What that means is that the insurance company cannot cancel the policy and raise the rates for an individual due to the change of their age or their health status. They can increase the premiums for an entire class of policyholders such as everyone in the State with the approval of the State insurance department.

To put my testimony in perspective, and to raise some issues that I think we have to keep in mind, I would like to point out some of the realities of long-term care insurance today. Despite its rapid growth in the last 4 or 5 years, and it has grown rapidly, I think, as a private product, it still is a very new form of insurance.

It is a very innovative form of insurance for us in the insurance industry. It embodies concepts of health insurance, life insurance and long-term disability insurance, but, it isn't any one of those. It is a different kind. It has benefits like health insurance, pays for nurses, nursing homes, therapists. It is somewhat like disability insurance in the sense that the need for it is really most accurately predicted by your ability to perform certain functions, rather than the presence or absence of a given disease. It is the ability to take care of oneself, or to carry out the activities of daily life that determines your need for long-term care on a chronic care basis.

And, it is similar to life insurance in the way that the premiums are structured. This is the key part of my testimony; that is, how it is priced, how the premiums are structured. The significant feature of all of these policies is that they actually pre-fund the benefits by building reserves on money to help fund the future outlays. Most of the products on the market today are aimed at older people. They are intended to try to offset at least some of the costs associated with chronic care and old age.

They pay a fairly large benefit over a short period of time; therefore, there is a need to build up funds to pay those benefits when they are needed. This is done by charging what is known as an age-related level premium. That is very similar to the kind you pay to life insurance, the whole life insurance. It means that the premium remains the same over the life of the person who has bought the policy. That is so that it enables the insurance company to spread the cost of the policy over the expected lifetime of the buyer.

The purchaser will pay the right premium for his age at the time that he buys the policy. And, the purchaser is not subsidizing the premium of other ages. That is part of the reason that it costs more at higher ages and less at younger ages. They are also lower if a person takes out a policy when, let's say, they are 50 or 55, than someone at age 75, because they will just be paying over a longer period of time, and they also have more impact of interest earnings

over time. Interest earnings help build up more money in the reserve.

Another reality I think we have to face is that long-term care insurance is not for everyone, at least not for today. Many older households cannot afford it. I think that it is just a fact that a soundly rated product might be prohibitively expensive at very high ages. That is one reason why it is not offered at very high ages, it is just too expensive to even afford. Some people can't buy it and some people should not buy it if it is going to deprive them of their income for essential living activities. Many people who might like a policy today who may be 80 or 90 years old, would like to have bought it 10 years ago, but it wasn't on the market 10 years ago, and that is unfortunate. If they were able to buy it at that time they would have been able to buy it. The products are definitely designed to offset the cost associated with illness among the elderly.

As we have heard today, there are other segments of the population that need long-term care. They may even need skilled care on a long-term basis in the way that the Kaisenger family described, instead of just custodial care. But, the fact that there are different population groups that need long-term care, the fact that they even use some of the same services does not necessarily imply that a single financing method is right for all of them.

Private insurance may not be an alternative in all cases, and we can come back to that. I think this heightens the importance of a creative combination of approaches as to how we pay for this problem.

I would like to comment on the specific charge that you gave me which is what the challenges are that insurance companies face in trying to offer these products. As I said this is a new business for us and it does present many challenges. I will outline those briefly and then speak to them.

One is an adequate market of insurable persons. People have to be aware of the need for long-term care and what it costs, the interest in it or even be willing to consider such a policy—a well-designed product with genuine benefits that really meet people's needs.

Very importantly, we want to come up with a very soundly priced policy, and that means that the premiums have to generate enough income to pay all the claims and all of the other expenses when they come.

We need some flexibility to be able to design these products to meet changing needs, and very importantly, the insurance companies have to use risk management techniques that support the basic principles of insurance that allow us to manage the product correctly.

Although we face challenges in designing and marketing our product there is an uncertainty in the legal and regulatory policy areas. The greatest challenge for us is to set the correct premium and determine the financial risk involved. So, that is what I would like to focus on.

I would like to explore some of those issues that contribute to risk for the insurance company and tell you more about them because they become features of the policy, and sometimes people

don't understand why they are there, and some of them are there for very, very good reasons.

First our pricing model must predict the income that we need to come from the premium in order to pay for the expenses as they come in. We must project how many people will go into benefits and when, and which method they will use, how long they will stay, and at what level of care. Since people buy these policies and may not use them for a few years, we have to do that for a long period of time. We may have to project for 10 or 20 years into the future as to what is going to happen.

One of the challenges facing the insurers, and I would submit also facing the public sector, in trying to price these policies, is where to get the necessary data to determine these utilization patterns. For the insurance company the best data is that which is derived from our experience in selling a particular product. Its experience of an insured population is not always the same as that of the population as a whole, but because these policies are so new, the insurance companies don't have a great deal of this data. Despite the absence of ideal data though, insurers can build a reliable model for pricing the long-term care policies by using data from public sources, and quite a bit of that is available, in making prudent assumptions and giving attention to proper policy details.

For us, a sound policy means that it is correctly priced or rated and that it will pay the benefits as it is intended, as we promised. Because of the many unknowns it is considered sound for us to build in some limits on what we will pay out, and not to have it completely open-ended. Those limits are typically the things that I cited, an amount per day or an overall amount in the lifetime of the customer that can be paid out.

The next challenge facing the insurers is to control something that is called "adverse selection," or selection against the insurer. The concept of adverse selection is simple. Persons who are most likely to need the benefits are also most like to seek to purchase the insurance, and from a consumer standpoint, that is only human nature. No one is doing anything wrong when they try to do that. But, for us as an insurance company, the goal is that we must create a pool. In projecting the amount of benefits to be paid, we estimate how many people are going to use the benefits, and the incidence and number of frequency of the number who bought it. Our goal is to create a pool of people and insure those who bought this policy who will have an average incidence of claims consistent with those in our projection.

If we don't do that, if fewer healthy people come into the pool and use more benefits, then it will turn out that the premium income was what was wrong and was inadequate. It was just a simple mathematical problem, but not a very simple problem for us. So, from our standpoint, we need to try to bring in people that will fit the projections that we made. They don't have to look like the rest of the population. They may be more or less healthy but they have to look like what we thought they were going to look like, in order for the price to be right.

Adverse selection is minimized when you insure a lot of people in a large group but as I think you know, most of these policies are

purchased by individuals, and most of them are purchased by those who require it, the average age of a purchaser being around 70.

So the primary way the insurance creates a sound pool for individual products is through individual underwriting. This is known as medical underwriting. Virtually all the policies do this today. This means at the time that someone applies, there will be questions about their medical status and their health and the insurance company will have to decide if they can accept them and take them into the insured pool. In other words, to sell them a policy or not.

Policies also have been limited to a maximum age of around 79 or 80, although some of these are increasing up to 80 to 85. Another challenge we are faced with is the control of something that is called "insurance-induced demand." Also a very simple concept, this means that a person is more likely to incur expenses for a service if they know they have insurance to pay for it.

We know that for every person living in the community today, that for every person living in a nursing home, there are probably a couple of people living in the community who are just as disabled, and we know that some 80 percent of care is already given by family members. So there could be some substitution of pay care for nonpay care. And, we have to consider that when we price the products.

The typical features that help control that are things like deductibles or deductible periods, simply meaning that the insured must pay for some of the first days of care, for the first 2 months of care, or for the first month of care, or a sharing of the cost on an ongoing basis throughout the duration of the care.

Insurers are also wrestling with the issues confronting the public programs which pay for long-term care, and I think some of our other panelists may comment further on this. But how do you decide if the long-term care services are needed and when they should begin and how do you treat everybody the same, and are you fair? And this really has to do with some measure of disability activities of daily living. There are assessment tools and a number of efforts that have gone on for programs at State and local levels that may help insurers, but they weren't developed for the insurance industry. We don't know exactly how they will work for us.

I would like to just comment briefly on what I think the relative roles are between the government and private industry. I think that there can be a combination of financing. Government can encourage individuals to save and insure for their long-term care, and frankly, most people who are working and who are younger today and could pay for much of their long-term care, if the right products were available now. I think government could consider tax policies which would provide incentives to individuals and employers to offer this kind of insurance.

In addition, I believe that both the Federal and State governments should continue to finance long-term care for those who cannot afford to protect themselves. Some people will exhaust their private means of support. Some people will never be able to afford private insurance. The Medicaid program is the largest that does that today, and it probably needs to be reformed in a number of areas, some of which you have heard about today.

Another important role for government, particularly at the State level, is the protection of consumers in setting standards and appropriate regulations for this kind of insurance. And the insurance industry through the Blue Cross and Blue Shield Association and the Health Insurance Association of America working, with the National Association of Insurance Commissioners, have promoted model laws and regulations to govern long-term care insurance. The model law has been adopted in some 42 States and is pending in five more including Pennsylvania.

And, finally, I believe that government and the insurance industry have the shared responsibility of an enormous task which was certainly brought out this morning: educating the public about the potential need for long-term care, how much it costs, the fact that their current insurance policies don't pay for it and the facts about buying long-care insurance that will help them protect themselves.

I would like to thank you for the opportunity to appear before you today. I think private insurance is very new, it is changing, it is growing, it will no doubt be improved and expanded. It will not replace the role of government in providing assistance to certain segments but it may be an important element in what I think is an inevitable public/private partnership to address this complex financial challenge.

Thank you.

[The prepared statement of Ms. Stagg follows:]

TESTIMONY

of

Betty M. Stagg

Director - Product Development for the Aging

INDEPENDENCE BLUE CROSS

on

LONG TERM CARE INSURANCE

before the

Subcommittee on Health and Long Term Care

Select Committee on Aging

U.S. House of Representatives

September 15, 1989

Philadelphia, Pennsylvania

Mr. Chairman and members of the Committee, I am Betty Stagg, Director of Product Development for the Aging, Independence Blue Cross. Independence Blue Cross is a health insurer and employee benefits company with a unique social mission. We provide health insurance and related services to more than 2,000,000 subscribers in Southeastern Pennsylvania. Created in November, 1938, Independence Blue Cross is one of 73 Blue Cross/Blue Shield Plans throughout the nation. Each of these Plans is an autonomous organization affiliated with the national Blue Cross and Blue Shield Association.

I am pleased to have the opportunity to appear before you today to testify on the development of private long term care insurance policies. I will comment on the importance of private financing for long term care, the current status of the long term care insurance market, and the challenges which insurance companies face in establishing actuarially sound long term care policies.

My testimony today is based on my knowledge and the extensive research into long term care insurance by Independence Blue Cross. It should not be construed as descriptive of a particular Blue Cross product or the position of the Blue Cross and Blue Shield Association.

The Importance of Private Financing for Long Term Care

There is a recognition that long term care is an important national issue which must be addressed through a combination of public programs and private market approaches. The enormous cost of long term care, both today and when the baby boom generation reaches old age in the next century, demands both immediate and long range solutions.

The cost of long term care is already significant for Americans as taxpayers who support public programs and as consumers who pay for it in direct out-of-pocket expenses. The nation now spends more than \$38 billion a year for care in nursing homes. State and national government programs pay almost one half of that amount. The rest falls to individuals and their families.

Long term care, particularly for nursing home stays, is the primary cause of catastrophic health expenses for older persons today. As the Select Committee on Aging pointed out in a recent report, forty percent of total direct out-of-pocket health spending by the elderly went to nursing homes. We also know that these expenses are not evenly distributed. The average nursing home cost of \$25,000 to \$30,000 per year can easily exceed annual income of many older households.

It is not surprising, therefore, that consumers are showing an increased awareness of the cost of long term care and are seeking a variety of ways to plan and prepare for it. These include Continuing Care Retirement Communities (life care), home equity conversion loans and, more recently, private long term care insurance.

A 1988 survey by the University of Maryland, Center on Aging, found that individuals saw long term care as a national priority, but recognized that government could be solely responsible for solutions. Furthermore, almost three fourths of those surveyed said they would be willing to purchase a private long term care insurance policy. More than fifty percent of the respondents were willing to pay \$100 per month for such a policy.

Many people will experience a need for some type of long term care as they grow older, possibly with severe financial consequences. Pooling the risk of catastrophic long term care expenses through an insurance mechanism is particularly appropriate. For example, the pooling of risk or exchange of a relatively small amount of premium dollars for protection against a much larger financial loss is more efficient than having to save enough money to cover an expensive long term care stay.

Although not everyone who needs long term care services today can buy this insurance (due to their age or poor health status), over one million persons have already availed themselves of this protection. Most of these policies have been purchased by individuals with an average age of purchase of around seventy. But products are beginning to be offered to younger persons through their place of employment. As a long range solution, a majority of the population could provide for their own long term care expenses through insurance.

There is great untapped opportunity for innovation and creativity in the private financing of long term care. In the past five years we have seen numerous improvements in long term care policies, the introduction of accelerated benefit life insurance and a growing interest on the part of employers in long term care insurance as part of economic security for retirees.

Status of the Long Term Care Insurance Market

The availability of private long term care insurance policies has increased greatly over the past few years. A recent survey by the Health Insurance Association of America estimates that 1.1 million policies had been sold as of the end of 1988.

The number of insurance companies offering long term care had increased from 16 in 1984 to 105 at that time. In addition, there are 19 Blue Cross/Blue Shield Plans that offer long term care insurance in their service areas.

Long Term Care Insurance is a very new line of personal insurance, which is sold primarily to persons between 50 and 80 years of age. These policies usually pay for skilled, intermediate and custodial care in a licensed nursing home. They may also pay for skilled and non-skilled nursing care in the home, homemakers, personal care aides and services such as adult day care, transportation and case management.

Policies usually pay a fixed amount per day, or actual charges for the service but only up to the daily benefit amount. The purchaser chooses the daily benefit amount when he or she buys the policy. Policies also offer several options for the duration of benefits, typically 3, 4 or 5 years. They may express the maximum lifetime benefit in terms of a number of days or dollars. Increasingly, policies are beginning to offer a periodic or annual increase in the daily benefit amount. This is intended to help the policy keep pace with the rising cost of care.

All long term care insurance policies contain some limitations or exclusions such as a pre-existing condition clause, deductible periods, and/or requirements for a prior stay in a hospital or nursing home. In addition, insurance companies use some method of evaluating an individual's health status to determine whether or not that person is insurable. This process is known as medical underwriting or individual underwriting.

Policies are priced based on the age of the buyer at the time of purchase, and are less expensive at younger ages. Most are Guaranteed Renewable, which means that the insurance company can only raise rates for an entire class of policyholders and cannot cancel the policy or raise rates for an individual due to changes in age or health status.

Realities of Long Term Care Insurance Today

Products on the market today are probably not as good as long term care products will be in the future. We must start somewhere, and insurance providers are still learning. As with any new product, competition, increased knowledge and expanding markets will lead to improvements.

Despite its rapid growth, long term care insurance is still a very new and innovative form of insurance. It embodies concepts of health, life, and long term disability insurance, but cannot be categorized as any one of these. Long term care insurance is similar to health coverage in the types of services and benefits that are paid: nursing home care and services of home health nurses, professional therapists and home health aides. It is similar to disability insurance in that the need for the benefits is most accurately predicted by the inability to perform certain functions rather than specific medical diagnoses. It is similar to life insurance in the way that premiums are structured.

In fact one of the significant features of private long term care insurance is that it pre-funds the benefits by building reserves to help fund future outlays. Long term care policies on the market today are intended to offset

the cost of chronic illnesses associated with old age. Since they pay a fairly large benefit over a relatively short period of time, there is a need to build up funds to pay those benefits when they are needed.

This is accomplished by charging an age related level premium similar to that used for whole life insurance. The level premium concept means that the premium remains the same over the premium paying period (generally the life of the policy holder), and does not increase because the policy holder grows older. The level premium approach enables the insurer to spread the cost of the policy evenly over the buyer's expected lifetime. The age rated premiums are lower for persons who take out a policy at younger ages because these persons probably will be paying for a longer time before they use policy benefits. There is also more impact of investment earnings on their premium payments. The purchaser pays the "right" premium for a person his age at the time of taking out the policy. The cost of policy sold to older age buyers is not subsidized by the premiums paid by younger buyers.

Long term care insurance is not for everyone. Many of today's older households cannot afford it. A soundly rated product is prohibitively expensive for people at an advanced age. The primary reasons for purchase of a policy are to protect financial assets, protect spousal income, avoid becoming a burden to loved ones and to obtain higher quality care. Nevertheless, no one should purchase this insurance if it will deprive them of income needed to meet essential living expenses. Likewise no one already enrolled in the Medicaid program should purchase a policy.

The long term care insurance products on the market today have been designed to offset some of the catastrophic cost associated with chronic illness among the elderly. There are other segments of the population which need long term care. However, the fact that different population groups need long term care and may be using similar services does not necessarily imply that a single financing mechanism is appropriate for all of them. Private insurance will not be a feasible alternative in all cases. This heightens the importance of a creative combination of approaches from the public and private sectors.

Challenges Insurers Face

Despite our growing awareness and knowledge, long term care insurance is still quite new and presents serious challenges to the insurance industry. In order to successfully enter this market, insurance companies must have the following:

- An adequate market of insurable persons
- A well designed product with genuine benefits that meet the needs of persons insured
- A soundly priced policy, based on premiums that the target market can afford and that will generate adequate income to pay the claims and other expenses which occur
- Enough flexibility in the regulatory environment to be able to adapt the product to changing circumstances
- Risk management techniques which support the basic principles of insurance and enable the insurer to manage the product.

Consumer awareness is increasing and the market is growing. Nevertheless, we face the marketing challenges of locating those who can and want to buy, educating the consumer about a complex topic, and asking people to think about a difficult subject-the possibility that they may someday be unable to care for themselves.

We also operate in an environment of much uncertainty with respect to legislation, regulation, tax policy and potential changes in public programs which pay for long term care.

The long term care delivery system is also evolving in terms of the quantity and quality of services available and is still dominated by the institutional service model. As the largest single source of reimbursement, government programs greatly influence price, supply and quality in the system. Service definitions, levels of care and types of available services vary widely from state to state. This creates challenges in product design, policy language and communication with consumers.

A fundamental but complex issue faced by insurers is the financial risk associated with these products. The challenge is to price these products correctly in the absence of data based on experience with an insured population.

I would like to explore further some of the specific issues in designing and pricing sound long term care insurance policies and the risk management techniques which insurers use to deal with these issues.

First, the actuarial model or pricing scheme must predict the income from premium payments and investment earnings and the claims expenses based on utilization. We must project how many people will go into benefits, when, for how long and at what level of care. Assumptions must be made about morbidity, mortality, interest rates, withdrawal and a number of other factors.

Since many of the persons who buy these policies will not use the benefits for 15 to 20 years or longer, we must make assumptions about all of the factors for a long time period. There may be enormous changes in the economy, the long term care delivery system, and the legal and regulatory environment during that time.

One of the challenges faced by insurers is where to obtain the necessary data to determine these utilization patterns. The most sound actuarial data is derived from an insurance company's experience in selling a particular product. Because long term care insurance is so new, most companies do not have a great deal of that data. It may be five years or more before insurers now entering the market will have experience based data with which to reassess the accuracy of their rates.

Despite the absence of an ideal data base, insurers can build a reliable model for pricing long term care policies by using existing data from public sources, making prudent assumptions and giving attention to sound policy design.

Sound policy design from the financial perspective, means a policy that we believe is rated correctly and will pay benefits as intended. Because of the many unknowns, it is considered sound to build in some limits on the amounts to be paid. Typical limits in policies today are a maximum dollar amount per day for various benefits, and a lifetime amount expressed in dollars or days of benefits.

The next challenge facing insurers is to control adverse selection or selection against the insurer. The concept of adverse selection, is simple. Persons who are most likely to need the benefits are also most likely to seek to purchase the insurance. The onset of need for long term care is gradual and somewhat predictable. Individuals know their chronic conditions, family history, availability of informal care and preference for services far better than the insurer. Therefore, there is probably a stronger opportunity for selection against the insurer in long term care than in hospital or acute care.

From the consumer standpoint, adverse selection is only human nature. But for the insurer it may mean that the pool of insured persons will be less healthy and have more claims than we projected, and, therefore, premium income will not be adequate to pay all claims. In projecting the amount of benefits to be paid, actuaries make assumptions about the incidence or frequency with which persons who bought the insurance will use the benefits. The goal of the insurance company is to create a pool of insured persons with an average incidence of claims consistent with those projections. If less people who are less healthy enter the pool and claims are much higher than projected, the premium income will be inadequate.

Adverse selection is minimized when we insure all of the persons in a large group that exists for some purpose other than acquiring insurance. For example, all those who work for a particular employer constitute such a group. However, thus far, most of the long term care policies have been purchased by persons of retirement age on an individual basis.

The primary way that insurers create a sound pool for insurance sold on an individual basis is through individual underwriting. For these products, thorough medical underwriting at the time of application is a prudent and necessary risk management technique. Virtually all long term care insurers in the market today evaluate the health status of applicants to determine their insurability. Insurers try to accept a pool of applicants who will have claim experience consistent with their projections.

Policies also usually limit the maximum age of eligibility for purchase to 79 or 80 years of age, as another way to limit adverse selection. Another control is the pre-existing condition limitation. When a policy has this feature, it will delay payment for services which are attributable to a disease or illness which the insured had immediately preceding the effective date of the policy. The delay in benefit payments may be from six months up to several years. However, legislation and regulation for long term care insurance generally limit the period to no more than one year.

Another challenge to insurers is the control of insurance induced demand. This means that a person may be more likely to incur expenses for certain services if he or she has insurance as a source of payment. We know that for every person residing in a nursing home today, there are two equally disabled persons

who are living in the community. Approximately 80% of the long term care received by such older persons is provided by family members. The substitution of paid care for even some of this unpaid care would definitely affect the cost projections for insurance policies.

Typical features which help control induced demand are deductible periods (during which the insured must pay for his own care) and required co-payments by the insured throughout the period of care. Also certain typical exclusions are aimed at this risk area. For example, many policies will not pay for unpaid care, or for benefits in case of self inflicted injury, suicide attempt or certain other unusual circumstances.

Insurers of long term care are wrestling with an issue also faced by public programs which pay for long term: how to decide if long term care services are needed and when they should begin. Public programs refer to this process as needs assessment or eligibility determination. In the insurance industry, we call it criteria to trigger the insured event. Thus far, many insurers have relied on physician certification of medical necessity for approval of a nursing home admission. But as companies expand their benefits to include such services as home health aides, homemakers and adult day care they must have a more accurate and reliable measure for when benefits should begin. Measures of disability are widely recognized as the best predictors of the need for and the use of long term care services. Assessment tools have been developed and used for many years in public programs to determine eligibility for long term care assistance. Nevertheless, these tools were not developed for use by the insurance industry, and are recognized to be in a state of change and improvement at this time.

It is widely acknowledged among long term care actuaries that the lack of insurance data make pricing of these policies difficult. It should be the goal of the insurer to set an adequate average lifetime premium at the time the policy is written and, therefore, not raise rates over the life of the policy. However, because actuarial data is so limited and it is necessary to make many assumptions in setting premiums, it is possible that future rate increases could be needed. Such increases would be unpopular among policyholders and subject to scrutiny from state insurance regulators. Uncertainty about the ability to obtain needed rate increases adds to the risk for insurers who offer these products.

Relative Roles of Government and Private Industry

The private long term care insurance industry has already benefited from public surveys, studies and data bases on long term care and the results of demonstration projects on long term care services. In addition, government can encourage individuals to save and insure for their own long term care cost as part of planning for economic security in retirement.

Government at the national level should consider tax policies which provide incentives for individuals and employers to purchase long term care insurance. These might include tax credits for long term care premium payments, deductibility of premiums as a health expense, and the tax favorable use of funds from individual retirement accounts or life insurance to purchase policies. It can also promote employer sponsorship of long term care insurance by clarifying its tax status in the Internal Revenue Code, allowing pre-funding of long term care

benefits, and specifying long term care as a benefit which can be included in cafeteria plans. It would also be desirable to confirm by law the recent IRS revenue ruling that certain reserves established by insurance companies for long term care policies and earnings on those reserves are deductible from federal taxable income.

Both federal and state governments should continue to help finance long term care services for those who cannot afford to protect themselves, for those (especially the very old) who have exhausted their private means of support and for those for whom private insurance will not be practicable. The Medicaid program is the largest existing federal/state program which meets this need. It should be reformed to include more community based care, to provide adequate reimbursement for high quality care and to improve the eligibility determination process.

Another important role for government, particularly at the state level, is the protection of consumers through setting standards and appropriate regulation. In general, the insurance industry has been supportive of standards to assure that consumers will receive value in long term care products. The Blue Cross and Blue Shield Association and the Health Insurance Association of America have worked with the National Association of Insurance Commissioners on a comprehensive model statute and model regulation for long term care insurance. Forty-two states have adopted the model Act or similar legislation and it is pending in five more states, including Pennsylvania.

Finally government and the insurance industry have a shared responsibility in the enormous task of educating the public about the potential need for long term care services, the cost of long term care and the facts about buying long term care insurance.

Conclusion

In closing, I would once again like to thank the Committee for the opportunity to appear before you today. Private long term care insurance is a new, innovative and rapidly changing product. It will no doubt be improved and expanded over the coming years. It may be only the forerunner of a variety of creative options for individuals to plan and save for their own long term care in retirement. It will not replace the role of government in providing assistance to certain segments of our population. But it may be an important element in an inevitable public/private partnership to address this complex challenge in the coming decade and the 21st century.

STATEMENT OF FRANK PODIETZ, M.B.A.

Mr. PODIETZ. Mr. Borski, I am Frank Podietz, Director of Operations of the Philadelphia Geriatric Center, a nonprofit organization with more than 35 years of experience in providing long-term care. For the sake of time, I will not read all of my prepared text but I would ask that it be included in the record and I will leaf through portions of it now.

Our Polisher Research Institute is supported by major grants from the National Institutes of Health, including the National Institutes on Aging and the National Institute of Mental Health, and private foundations. It carries out social, behavioral, and bio-medical research studies and demonstrations. I appreciate the opportunity to report on the ongoing research of the PGC into long-term needs. I commend the subcommittee for its continuing interest in this pressing issue.

Based on the PGC's clinical and research findings, I will address six major issues with respect to community-based long-term care. First, targeting an eligibility for services; second, case planning and management; third, expanding home and personal care services; fourth, services to support family caregivers; fifth, training and quality assurance for in-home service providers; and sixth, mental health care.

Our first recommendation is to target coverage for community-based long-term care services to older persons who have chronic physical or cognitive impairments and require sustained assistance with two or more activities of daily living. Comprehensive assessment of functional ability should be the basis to determine eligibility for coverage of long-term care services. I am pleased to say that the legislation that you support really acts on this recommendation directly.

Our second recommendation is to provide information and referral, case management, counseling, and education services to help older people and their families gain access to long-term care services and use them effectively. Research and clinical experience shows that older people and their family caregivers have great difficulty finding and using community-based services. In survey after survey, families indicate that they are unaware of the available community services and need help in understanding and accessing them.

A recent PGC study of 315 caregivers of spouses with Alzheimer's disease substantiated this problem on a local basis, and caregivers in a national study by the Office of Assessment ranked the need for assistance locating services as second only to the need for respite care.

Model programs across the country have demonstrated that high quality I&R and case management services can be powerful interventions to improve access to help and reduce fragmentation in service delivery. The national channeling project, for example, found that clients and family caregivers who received case management were more satisfied with services and reported greater satisfaction with life than those who did not receive case management. Although effective models of I&R and case management exist in

some communities, the need outpaces supply. In general, funding is quite inadequate.

A third recommendation is to expand coverage for personal care and homemaker services, which are the primary need of chronically-impaired older people living at home in the community. Yet, this form of nonmedical supportive care, which is crucial to daily functioning for millions of older Americans, is not adequately covered under current private and public insurance programs.

Compelling evidence of the need for expanded coverage for home and personal care services comes from the General Accounting Office's analysis in their 1982 National Long-Term Care Survey. That study showed that 22 percent of individuals with three or four ADL impairments, and 48 percent of those with five or six impairments, were not receiving all of the care they needed. The data suggests that some older people may be going without help because they cannot afford to purchase services, or because of shortages in the supply of services.

For most impaired older people, who live on limited incomes, purchasing services for an extended period on an out-of-pocket basis would be a catastrophic expense. As all of us have said, we have seen that dramatically demonstrated this morning.

Although promising developments are taking place in the private long-term care insurance market, coverage on a very broad basis is likely to expand at a very slow rate.

A fourth recommendation is to expand the focus of national long-term care policy to encompass the needs of family members caregiving for aging relatives. As one important step, coverage for respite services for family caregivers should be broadened to include adult day care and nursing home options.

Despite persistent myths to the contrary, 35 years of research have established conclusively that the family has always been and continues to be the main provider of long-term health and social support for older people. Today, more families provide more care, and more difficult care, to more older people for much longer periods of time than ever before in history.

The 1982 Long-Term Care Survey, sponsored by the U.S. Department of Health and Human Services, found that the vast majority of services to the elderly are provided by families not government and not private agencies. Families provide most of the medically-related services, personal care, household maintenance, and monitoring, and they often share their homes with the older person who can no longer live alone.

A central goal of any national long-term care policy should be to support these caregivers who are struggling "to do it all"—to fulfill their responsibilities to their aging relatives, their families, and their jobs. Respite care that offers temporary relief from the physical and emotional stresses of elder care is one such service. Its importance was recognized in the Medicare Catastrophic Coverage Act. I don't even want to say it, because we hear so many lovely things about it.

Mr. BORSKI. You don't have to remind me of that.

Mr. PODIETZ. At least you haven't been stoned. It provides reimbursement for up to 80 hours of in-home respite per year. Although this coverage was an important first step, data from a recent PGC

demonstration project indicate a need to expand coverage to include adult day care and institutional options as well as to increase the hours of covered care.

In a demonstration project supported by the Hartford Foundation and the Pew Charitable Trusts, PGC offered comprehensive assessment, case management, counseling and three forms of respite to 315 families who volunteered to participate in research on caregiving to Alzheimer's patients. Overnight stays in a nursing home, adult day care and in-home respite options were available, and a financial subsidy was provided to those who required it.

The project made it clear that caregivers need and want a range of respite care options. Approximately half of the families elected to use respite services. Of those, 60 percent used in-home respite, 38 percent used day care, and 15 percent used nursing-home respite during the project year. Although in-home respite was the most popular choice, all three forms were used in substantial proportions and responded to the unique needs of each family.

One concern that many of us share is that the expansion of entitlements will lead to limitless demand. Such fears proved unfounded in this demonstration. Although caregivers were offered, and even encouraged, to avail themselves of respite they obviously needed, only about half of them opted to use it, and this is despite the fact that caregivers to Alzheimer's patients are a service-needy and very high risk group. Furthermore, caregivers' requests for service were extremely modest and they were willing, even eager, to pay in accordance with their means. The provision of subsidized respite care is not a financial bottomless pit.

Our fifth recommendation is to establish quality assurance and training requirements for home care services to promote a high standard of care.

Findings from the PGC respite study underscore the importance of this concern to consumers. Those participants who offered criticisms of respite service cited lack of training and trained sensitivity on the part of in-home workers. Workers must be hired selectively and trained for the demanding tasks which they are asked to perform if we are to make families more comfortable with outsiders coming into their homes to give care to older relatives.

In addition to staff training, close supervision, specific standards of care, and consumer follow-up mechanisms such as satisfaction surveys and complaint procedures are important ingredients to ensure in-home quality. Backed up by monitoring and enforcement, such measures will help to assure consumers that care will be delivered in a manner that promotes their safety, their independence and their dignity.

Our final recommendation is to integrate mental health assessment and treatment into community-based long-term care services.

Health care and social services have been the traditional focuses of long-term care policy but mental health care, which is also a critical need of older persons with chronic disabilities, has not been addressed. The gap is not the result of a rejection of mental health care; rather, it has come about because mental health care has not been introduced into the long-term care agenda. Research shows that mental health problems, especially depression, are closely associated with chronic disabling illness.

P.G.C.'s Clinical Research Center, supported by long-term funding from the National Institute on Mental Health, recently investigated this relationship among nursing home and congregate housing residents. The study found that individuals with long-term care needs have higher rates of depression than the older population in general, and that that depression is associated with both physical and cognitive disabilities.

From a methodological perspective, the study demonstrated that depression and other mental health symptoms can be evaluated easily and accurately as part of a comprehensive long-term care assessment. The findings indicate that routine mental health assessment of individuals with long-term care needs is likely to uncover depression, dementia and other conditions that have an impact on daily functioning but which might otherwise go undetected and untreated.

Once identified, treatment of these problems can be integrated into an individual's overall plan of care that might include medical, rehabilitation and social services. The study shows the importance, and feasibility of integrating mental health into assessment and treatment of older people if we are to maximize their functioning and their quality of life.

On behalf of the Philadelphia Geriatric Center and of older people and their caring family members, I thank you for the privilege of presenting these views.

[The prepared statement with attachments of Mr. Podietz follows:]

Testimony
before the
United States House of Representatives
House Select Committee on Aging
Health and Long Term Care Subcommittee

by

Frank Podietz, M.B.A.
Director of Operations
Philadelphia Geriatric Center

September 15, 1989

Mr. Chairman and Members of the Subcommittee, I am Frank Podietz. I am Director of Operations at the Philadelphia Geriatric Center (PGC), a non-profit organization with more than 35 years of experience in providing long-term care. We care for more than 1,200 older people on our campus in nursing homes, high-rise apartment buildings with services, and a geriatric medical hospital. We also serve thousands of older people living in their own homes or with relatives by means of adult day care, home health care, a consultation and diagnostic center, in-home services, satellite medical offices, and a program of counseling and respite services for caregivers. PGC is a training center for health care and social service professionals, and offers numerous educational programs for the public.

The Polisher Research Institute, which is supported by major grants from the National Institute of Health, the National Institute of Mental Health and private foundations, carries out social, behavioral, and bio-medical research studies and demonstrations. Since its inception in 1959 as the first U.S. research center to be sponsored by a private geriatric facility, the Institute has maintained a strong tradition of applied research. Information gained through research has been vital in shaping PGC's services for older persons and their family caregivers.

The Institute's researchers have examined the psychological wellbeing of the elderly, their housing needs, the roles of family members as caregivers, the need for respite care, the special needs of Alzheimer's sufferers, and the impact of ethnicity on aging. In response, we have assembled a continuum of programs to support the populations studied. Our consultation and diagnostic center, home health service, specialized services for caregivers, community housing and Active Life fitness center are programs that were initiated as research or demonstration projects, and now are sustained by client fees, third-party reimbursement, or subsequent grants.

I appreciate the opportunity to report on the ongoing research into long-term care needs at PGC, and commend the Subcommittee for its continuing interest in this pressing issue. Based on PGC's clinical and research findings, I will address six major issues with respect to community-based long-term care: 1) targeting and eligibility for services; 2) case planning and management; 3) expanded home and personal care services; 4) services to support family caregivers; 5) training and quality assurance for in-home service providers; and 6) mental health care.

Our first recommendation is to target coverage for community-based long-term care services to older persons who have chronic physical or cognitive impairments and require sustained assistance with two or more activities of daily living. Comprehensive assessment of functional ability should be the basis to determine eligibility for coverage of long-term care services.

One in four of the nation's 31 million older Americans has a physical or cognitive impairment that may result in a need for long-term assistance. Of these individuals, 1.5 million live in nursing homes, but the vast majority -- the 6 million older people who are our focus today -- reside in their own homes in the community.(1)

Functional impairment in the older population is determined on the basis of the ability to perform activities of daily living (ADL). These activities -- toileting, ambulation, transferring in and out of bed, eating, dressing, bathing and grooming -- are the skills most necessary for life preservation but the most likely to fail in the face of physical and mental disability.(2) The most common ADL limitations are difficulty with walking (19 percent), bathing (10 percent) and getting outside the house (10 percent).(1) The need for assistance with eating and moving around the home have been shown to be most closely associated with institutionalization.

An estimated 2.4 million older people living in the community are limited in their ability to perform one ADL, 1.2 million have two ADL limitations, 700,000 have 3 ADL limitations, 500,000 have 4 ADL limitations, and 1 million have 5 or more ADL limitations.(1) The number of ADL limitations rises with age. Almost half (49 percent) of those age 85 or older have difficulty with one or more ADLs, as compared to only 17 percent of those age 65-74. At a minimum, the 3.4 million older persons with two or more ADL limitations should be covered under public long-term care entitlements.

We have at our disposal today comprehensive assessment instruments, such as the PGC Multilevel Assessment Instrument (MAI), developed by Lawton and his research team, to measure ADL performance as well as other aspects of functioning.(3) The MAI

and similar instruments are used nationwide. These tools have been shown to have clear and objective criteria, to detect changes in functional status over time, and to uncover the types of functional problems that necessitate long-term care services.

The instruments also are sensitive to functional limitations linked to cognitive impairment. The presence of dementia or a related disorder may result in confusion, disorientation, memory loss and behavior changes that make it difficult for an older person to function independently, without substantial supervision or cueing by a caregiver. Those affected may be physically able to perform activities of daily living but may fail to do so without help. These individuals also should be covered by federal entitlements.

Because they are so closely related to long-term care service needs, impairments in ADL ability and cognitive functioning are appropriate criteria on which to base eligibility for coverage of community long-term care services. Utilizing functional and cognitive assessment as the basis for federal entitlements would constitute an important step toward rationalizing the long-term care benefit structure, and targeting resources to those most in need.

Moreover, assessment of ADL and cognitive impairment, in addition to physical health, ability to perform instrumental activities of daily living (such as shopping, cooking, and housecleaning), psychological wellbeing, social relationships, environment, and the status and needs of family caregivers is good clinical practice. Comprehensive assessment enables older people, their families and their advocates to identify the full spectrum of needs and to coordinate a responsive plan of care.

Our second recommendation is to provide information and referral, case management, counseling, and education services to help older people and their families gain access to long-term care services and use them effectively.

Research and clinical experience show that older people and their family caregivers have great difficulty finding and using community-based services. In survey after survey, families indicate that they are unaware of the available community services and need help in understanding and accessing them. A recent PGC study of 315 caregivers of spouses with Alzheimer's disease substantiated this problem on a local basis, and caregivers in a national Office of Technology Assessment study ranked the need for assistance locating services as second only to the need for respite care.(4)

In part, this problem arises because of the complexity of long-term care needs, and the fragmentation of existing systems of care. Older people with chronic impairments typically have multiple needs that cross the boundaries of medical care, social

services, mental health, income maintenance and aging services. Nevertheless, each of these services is operated, administered and financed as a discrete system. They vary in terms of eligibility criteria (such as age, diagnostic, functional, financial, and residential standards), funding sources, regulations and auspice. Also, providers in one field often lack knowledge about the services provided by another.

For impaired older persons and their caregivers, who may themselves be aged, the complexity and discontinuity of existing systems can be daunting obstacles to care. Information and referral programs that educate the public about the array of community services constitute an important first step toward addressing the problem.

However, older people and their families, who are overwhelmed or distrustful of the formal system, still may face substantial impediments to receiving service. They may have difficulty identifying multiple problems, contacting and coordinating providers, or comprehending the bewildering assortment of entitlements, regulations and eligibility criteria. Psychological factors, such as denial of a disability, may bar others from receiving the help they need. Many older individuals and their families need help sorting out their problems, understanding how the available services can help, and arranging care.

Model programs across the country have demonstrated that high quality information and referral and case management services can be a powerful intervention to improve access to care and reduce fragmentation in service delivery. The national Channeling project, for example, found that clients and family caregivers who received case management were more satisfied with services and reported greater satisfaction with life than those who did not receive case management.(5)

Two programs at PGC, the In-Home Service Program, sponsored by the Area Agency on Aging, and the Counseling for Caregivers Program, supported by The Pew Charitable Trusts and The William Penn Foundation, serve more than 1,000 older people and their families annually. Both programs provide information and referral and case management services that include comprehensive assessment, care planning, arrangement and monitoring of services, reassessment, counseling, advocacy and education. Each component is crucial to enabling families to define their needs, learn how the available options can benefit them, and select the services best-suited to their individual situations.

Although effective models of information and referral and case management exist in some communities, the need outpaces supply. In general, funding for such services is limited, and resources are targeted primarily to the very poor or near poor. As a result, many individuals who could benefit from them are excluded.

It is the role of government to educate older people and their families about available entitlements as well as to help them gain access to and use benefits. A commitment to adequately financed public education, information and referral, and case management services is vital to creating a coordinated and effective long-term care policy.

A third recommendation is to expand coverage for personal care and homemaker services, which are the primary need of chronically impaired older people living at home in the community.

The principal need of the long-term care population is prolonged assistance with basic personal and home care tasks. Yet, this form of non-medical supportive care, which is crucial to daily functioning for millions of older Americans, is not adequately covered under current private and public insurance programs.

Medicare covers some of these services under its home health benefit, but to be eligible, an individual must require skilled nursing care on an intermittent basis, or physical or speech therapy. This benefit is of limited usefulness, since most chronically impaired older people do not require skilled care to remain in their homes.

Medicaid and other public programs also provide coverage for home and personal care but they are targeted primarily to the poor. Moreover, funds tend to be limited and services are in desperately short supply. A recent study commissioned by The Pew Charitable Trusts reported that, in Philadelphia, more than 1,000 older people were on waiting lists for in-home care.(6) Among the elderly clients of our In-Home Service Program, most of whom live alone, personal and home care services are the major need.

Compelling evidence of the need for expanded coverage for home and personal care services also comes from a General Accounting Office analysis of the 1982 National Long-Term Care Survey. This study showed that 22 percent of individuals with three or four ADL impairments, and 48 percent of those with five or six impairments, were not receiving all of the care they needed.(7) The data suggest that some older people may be going without help because they cannot afford to purchase services, or because of shortages in the supply of service.

For most impaired older people, who live on limited incomes, purchasing services for an extended period on an out-of-pocket basis would be a catastrophic expense. Although promising developments are taking place in the private long-term care insurance market, coverage is likely to expand slowly. Coverage of home and personal care services under Medicare would enable the majority of older people with chronic disabilities to receive care at home, where they overwhelmingly prefer to be, without the risk of financial impoverishment.

A fourth recommendation is to expand the focus of national long-term care policy to encompass the needs of families caring for aging relatives. As one important step, coverage of respite services for family caregivers should be broadened to include adult day care and nursing home options.

Despite persistent myths to the contrary, 35 years of research have established conclusively that the family has always been and continues to be the main provider of long-term health and social support to older people. Today, more families provide more care, and more difficult care, to more older people over much longer periods of time than ever before in history.

The 1982 Long-Term Care Survey, sponsored by the U.S. Department of Health and Human Services, found that the vast majority of services to the elderly are provided by families -- not government or private agencies. Families provide most medically-related services, personal care, household maintenance, and monitoring, and they often share their homes when the older person can no longer live alone. Formal services account for less than 15 percent of "helper days of care" in the community (including home health, homemaker/chore service, adult day care programs, etc.).(8)

Studies also demonstrate that families continue to care for disabled relatives for years, often at substantial economic and social cost to themselves and society. Caregivers, one-third of whom are over age 65, may have their own health problems, and become exhausted, depressed and isolated. Approximately 50 percent of family caregivers experience significant mental and emotional strains from heavy caregiving to severely disabled older persons, and about 20 percent experience deterioration in their physical health. Nevertheless, they are enormously loyal, enduring for many years despite the severe strain they experience.

Other costs may include lost wages, when a family member leaves the workforce to care for an aging relative. A PGC study, since confirmed by national data, found that significant proportions of family members quit their jobs or cut back on their work hours because of the demands of caregiving.(9,10) Approximately 25 percent of all working people are involved in providing help to a disabled elderly family member.(11)

A central goal of national long-term care policy should be to support these caregivers who are struggling "to do it all" -- to fulfill their responsibilities to their aging relatives, their families, and their jobs. Numerous studies have shown that services from the formal support system do not encourage families to shirk caregiving. Rather, such services complement and supplement family care and strengthen the family's caregiving capacities.

Respite care, that offers temporary relief from the physical and emotional stresses of elder care, is one such service. Its importance was recognized in the Medicare Catastrophic Coverage Act of 1988, which provides reimbursement for up to 80 hours of in-home respite per year for individuals who have met specified medical or medication deductibles. Although this coverage was an important first step, data from a recent PGC demonstration project indicate a need to expand coverage to include adult day care and institutional options as well as to increase the hours of covered care. On average, the current benefit offers only about one and one-half hours of relief per week to family members caring for disabled relatives.

In a demonstration project supported by The John A. Hartford Foundation and The Pew Charitable Trusts, PGC offered comprehensive assessment, case management, counseling and three forms of respite to 315 families who volunteered to participate in research on caregiving to Alzheimer's patients.⁽¹²⁾ Overnight stays in a nursing home, adult day care and in-home respite options were available, and a financial subsidy was provided to those who required it.

The project made it clear that caregivers need and want a range of respite care options. Approximately half of the families elected to use respite services. Of these, 60 percent used in-home respite, 38 percent used day care, and 15 percent used nursing-home respite during the project year. Although in-home respite was the most popular choice, all three forms were used in substantial proportions, and responded to different needs.

Day care, for example, offers the advantages of freeing caregivers for a relatively long continuous block of time during the day, and providing stimulation and socialization for the impaired person. This is a particularly useful option for working caregivers. Some care recipients, however, become too impaired for the day care setting. For them and their caregivers, in-home respite may be the most appropriate alternative. In our study, institutional stays were used primarily when caregivers were hospitalized, needed a brief vacation, or needed time to plan long-term care by visiting nursing homes. This alternative is especially helpful for caregivers of the very severely impaired since nursing homes are staffed and equipped to provide this level of care.

Thus, no single respite option can meet the needs of all caregivers and care recipients. Instead, flexible options are necessary to respond to caregivers' varying circumstances, and care recipients' varying degrees of disability. Assessment, case management, education and counseling services also are critical to enable caregivers to gain the maximum benefit from respite.

One concern that many of us share is that expansion of entitlements will lead to limitless demand. Such fears proved unfounded in this demonstration. Although caregivers were offered, and even encouraged, to avail themselves of respite they obviously needed, only about half of them opted to use it -- this despite the fact that caregivers to Alzheimer's patients are a service-needy and high risk group. Furthermore, caregivers' requests for service were extremely modest and they were willing, even eager, to pay in accordance with their means. Forty percent of respite users contributed to the cost of care. The provision of subsidized respite care was not a financial bottomless pit.

In this project, as in and many others, family caregivers demonstrated a heroic determination to care for aging relatives. To sustain this effort, all they need is a relatively small amount of help. The project documents the need for, and viability of, a partnership between the formal system and family caregivers. The expansion of respite options covered under Medicare, and the provision of assistive services, would be an important step to affirm this partnership.

A fifth recommendation is to establish quality assurance and training requirements for home care services to promote a high standard of care.

Just as significant effort has been devoted to the regulation of nursing homes, strong initiatives to guarantee the quality of home and personal care services also are essential. In the unsupervised, possibly isolated environment of a chronically impaired older person's home, the potential for erratic, poor, or even abusive care is a serious threat. A commitment to expand the availability of community-based long-term services must be matched by an equally deep regard for the quality of care.

Findings from the PGC respite study underscore the importance of this concern to consumers. Those participants who offered criticisms of respite service cited lack of training and trained sensitivity on the part of in-home workers. Workers must be hired selectively and trained for the demanding tasks which they are asked to perform if we are to make families more comfortable with outsiders coming into the homes of their older relatives.

In addition to staff training, close supervision, specific standards of care, and consumer follow-up mechanisms such as satisfaction surveys and complaint procedures are important ingredients of in-home quality assurance. Backed up by monitoring and enforcement, such measures will help to assure consumers that care will be delivered in a manner that promotes their safety, independence and dignity.

A final recommendation is to integrate mental health assessment and treatment into community-based long-term care services.

Health care and social services have been the traditional focuses of long-term care policy but mental health care, which is also a critical need of older persons with chronic disabilities, has not been addressed. The gap is not the result of a rejection of mental health care; rather, it has come about because mental health has not been introduced into the long-term care planning agenda. The time has come to recognize mental health as an essential component of a coordinated community-based long-term care strategy.

Research shows that mental health problems, especially depression, are closely associated with chronic disabling illness. PGC's Clinical Research Center, supported by long-term funding from the National Institute of Mental Health, recently investigated this relationship among nursing home and congregate housing residents.(13) The study found that individuals with long-term care needs have higher rates of depression than the older population in general, and that depression is associated with both physical and cognitive disability. Nursing home residents experience a rate of major depression four times higher than that of the overall older population. Those with long-term care needs in the community also have a higher rate of depression than the older population as a whole, although the rate is lower than for nursing home residents.

From a methodological perspective, the study demonstrated that depression and other mental health symptoms can be evaluated easily and accurately as a part of comprehensive long-term care assessment. With the appropriate use of structured assessment tools already in existence (many developed at PGC), nonprofessional staff were able to obtain reliable mental health assessments even from moderately to severely impaired older persons.

The findings indicate that routine mental health assessment of individuals with long-term care needs is likely to uncover depression, dementia and other conditions that have an impact on daily functioning but which might otherwise go undetected and untreated. Once identified, treatment of these problems can be integrated into an individual's overall plan of care that may also include medical, rehabilitation and social services. The study shows the importance -- and feasibility -- of integrating mental health into assessment and treatment of older people if we are to maximize functioning and quality of life.

On behalf of the Philadelphia Geriatric Center and of older people and their caregiving families, I thank you for the privilege of presenting these views.

Reference Notes

1. Keenan, M.P. 1989. Changing Needs for Long-Term Care: A Chartbook. Washington, DC: American Association of Retired Persons.
2. Lawton, M.P. 1986. Functional assessment. In Geropsychological Assessment and Treatment, L. Teri, P. Lewinsohn (eds.). New York, NY: Springer Publishing Company.
3. Lawton, M.P., Moss, M., Fulcomer, M., Kleban, M. 1982. A research and service oriented multilevel assessment instrument. Journal of Gerontology 37 (1): 91-99.
4. Office of Technology Assessment, U.S. Congress. 1987. Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias (OTA-BA-323). Washington, DC: U.S. Government Printing Office.
5. Kemper, P., Applebaum, R., Harrigan, M. 1987. Community care demonstrations: What have we learned? Health Care Financing Review 8 (4): 87-100.
6. The Pew Charitable Trusts. 1989. Targeting for the Future: Health Care in the Philadelphia Region. Philadelphia, PA: The Pew Charitable Trusts.
7. U.S. General Accounting Office, 1988. Long-Term Care for the Elderly: Issues of Need, Access, and Cost (GAO/HRD-89-4). Washington, DC: US General Accounting Office.
8. Doty, P., Liu, K., Wiener, J. 1985. An overview of long-term care. Health Care Financing Review 6 (3): 69-78.
9. Brody, E. 1985. Parent care as a normative family stress. The Gerontologist 25 (1): 19-29.
10. U.S. House of Representatives, Select Committee on Aging. 1987. Exploding the Myths: Caregiving in America. Washington, DC: US Government Printing Office.
11. The Travelers Insurance. 1985. The Travelers Employee Caregiver Survey. Hartford, CT: The Travelers Companies.
12. Lawton, M.P., Brody, E.M., Saperstein, A.R. 1989. A controlled study of respite service for caregivers of Alzheimer's patients. The Gerontologist 29 (1): 8-16.
13. Parmelee, P.A., Katz, I.R., Lawton, M.P. 1989. Depression among institutionalized aged: Assessment and prevalence estimation. The Journal of Gerontology 44 (1): M22-29.

ATTACHMENT I

PHILADELPHIA GERIATRIC CENTER

Philadelphia Geriatric Center (PGC) is the most comprehensive provider of healthcare services to seniors in the Delaware Valley. PGC offers a coordinated system of health and social services for older people and their families. Throughout the aging cycle, these services provide a continuum of care in a variety of settings including institutional, community and an individual's own home.

Older persons, from the fit to the frail, turn to us for an array of health, medical, rehabilitative, spiritual, social and psychological services. PGC responds with services and programs which meet the needs of our older generations while remaining ever supportive of families and caregivers. All of these are based on the experience and research that have gained PGC a national reputation for expertise in geriatrics.

A Jewish sponsored, nonprofit organization, PGC is committed to continuing its distinguished heritage of care and respect for persons as they age. PGC is a constituent of the Federation of Jewish Agencies of Greater Philadelphia, and United Way.

PGC Services Include:

- | | |
|-------------------------------------|--------------------------------------|
| *Nursing Home Care | *Alzheimer's Evaluation & Counseling |
| *Retirement Living | *Psychological Services |
| *Hospital Care | *Programs for Industry |
| *Medical Practices | *Senior Health & Fitness Program |
| *Adult Day Health Center | *Care Assessment & Planning |
| *Home Health Care | *Professional Education |
| *Outpatient Health Services | *Research |
| *Consultation & Diagnostic Services | *Speakers Bureau |
| *Rehabilitation Services | |

NURSING HOME CARE

The Robinson/ Lewin Buildings and the Solms Pavilion together contain 418 nursing care beds in which skilled nursing care and intermediate care are provided for individuals over age 65.

The Slev Pavilion of the Weiss Institute, a specially designed long-term care facility for 120 older people with Alzheimer's Disease and related disorders includes a 40 bed unit certified to accept post-hospital or direct admissions for skilled nursing entitlement under Medicare.

The nursing home provides a holistic, team approach - caring for the total individual and his or her family, not just a medical problem. Each resident receives the services of physicians, physician assistants, psychologists, nurses, social workers, rehabilitation therapists, and other allied health professionals, as well as the services of a full-time rabbi. We believe that each resident is unique and care includes concern for each person's physical, social, emotional and spiritual well-being.

RETIREMENT LIVING

York House North and York House South, two apartment buildings for the aged, provide efficiency and 1-bedroom apartments for approximately 500 persons. Services include two Kosher meals daily, weekly cleaning service and linens, medical care, 24 hour emergency on-site nursing coverage, prescription medications, professionally supervised recreational programs, religious services and cultural events. Tenants who require long-term care, because of a change in their condition, receive priority admission to PGC's nursing home facilities.

HOSPITAL CARE

The Friedman Hospital a 28 bed acute care hospital, which is fully accredited by the Joint Commission on Accreditation of Health Care Organizations. A complete spectrum of specialty services is offered including an 8 bed geriatric rehabilitation service. The comprehensive rehab unit provides individualized treatment program directed by a full-time physiatrist and staffed by physical and occupational therapists, speech pathologists and audiologists. The Friedman Hospital team of geriatric specialists strive to help geriatric patients achieve and maintain their ability to function independently.

OUT PATIENT HEALTH SERVICES

PRIME HEALTH from PGC-Einstein offers innovative medical care to senior adults living in the community at three locations (Logan, City Line area and the Northeast). In addition to providing internal medicine and other medical specialties, the practices also provide transportation, assistance completing medical forms, and health education.

Anna and Benjamin Poland Geriatric Health Center. Through its outpatient department, PGC's health services are available to persons 62 or older who live in the community. These services include 21 specialty clinics ranging from medical and surgical sub-specialties to dentistry, podiatry and audiology. The outpatient department provides care to participants in all PGC programs as well as referrals from community clients.

HOME HEALTH CARE

Home Health Care. A Medicare certified Home Health Care Agency provides skilled nursing care, physical, occupational, and speech therapy when ordered by a physician. Medical social workers are available to provide assistance with social, emotional and financial problems. The agency also provides home health aides to help with personal care and household assistance.

GERIATRIC ASSESSMENT SERVICE

Baer Consultation and Diagnostic Center. This service is available to older people who reside in the community and has also served individuals from many parts of the United States. At the conclusion of the comprehensive work-up, the evaluation team meets to review findings, determine the diagnosis and develop a plan of treatment. The team then meets with the patient and family to communicate their findings and recommendations and, if necessary to make referrals to appropriate resources and facilities for further treatment.

ADULT DAY HEALTH CENTER

The Helen L. Weiss Adult Day Health Center provides a structured therapeutic day care experience for older persons who suffer from moderate-severe physical and/or cognitive impairments. Through social/recreational therapeutic programming and the provision of medical, health and rehabilitation services, participants are assisted to improve and/or maintain their maximal level of functioning.

COMMUNITY SERVICES

IN-HOME SERVICES PROGRAM. The In-Home Service Program provides case management for older persons and their families living in the community. By linking individuals in need, directly or by referral, to the appropriate health, financial, social, psychological and homemaking and personal care services, clients are helped to remain in their homes as long as possible. The program's priority target population is the frail elderly, drawn from among the 22,000 older people living in the Logan, Olney, Feltonville, Fern Rock and East Oak Lane communities.

COUNSELING FOR CAREGIVERS: Coping With Alzheimer's Disease and Related Disorders. Counseling for Caregivers is designed to address the multiple and complex needs of families caring for dependent older relatives. A team of geriatric mental health professionals are available by telephone, and by office and home visits to residents of the Greater Philadelphia area. This program helps caregivers by providing education about disease, techniques to manage problem behavior, linkage to needed community resources such as medical supervision, day care, respite care, and counseling to alleviate family stress and assistance with long-term planning.

COMMUNITY HOUSING. Twenty-eight older people live in remodeled homes adjacent to PGC's main campus. Each of the three apartments in each house is a self-contained unit with private bedroom, kitchen, and bathroom. The living room is shared. Included in the basic rental are building maintenance, a telephone "hot line" from each house to the PGC hospital for medical emergencies, and social services to help the older people during the application and moving phases. Housekeeping and frozen daily meals are optional "extras" that can be purchased from the Center at nominal cost.

PSYCHOLOGICAL SERVICES

Clinical Psychology. The clinical psychology department of PGC provides psychological services, upon physician referral, throughout the PGC continuum of care (inpatient and outpatient programs, satellite offices). Services include individual, group and family psychotherapy, psychological and neuropsychological testing, clinical evaluation and staff consultations. The department trains pre-doctoral and post-doctoral fellows from graduate programs nationwide. Although the department has a primary clinical focus, some members of the department are also engaged in research activity related to clinical issues.

ACTIVE LIFE

SENIOR HEALTH AND FITNESS PROGRAM offers a new concept in health and fitness specially developed for people over 62 who want to stay active, keep fit and feel younger. The program provides a pre-exercise evaluation and fitness profile; nutrition counseling; a 12-week monitored exercise program in our state-of-the-art exercise laboratory and follow-up testing. Activelife is staffed by a team of health professionals trained in caring for mature adults, including specialists in cardiology, pulmonary medicine and rheumatology.

RESEARCH

EDWARD AND ESTHER POLISHER RESEARCH INSTITUTE. The Research Institute conducts research on all aspects of the aging process and is fully staffed by psychologists, sociologists, anthropologists, social workers and research physicians. Total research staff numbers about 70, many of whom hold Ph.D.'s in their respective disciplines. The research is supported by private donations, governmental agencies such as the National Institutes of Mental Health and the National Institute of Aging, and private foundations.

PROFESSIONAL EDUCATION

Professional Education. PGC is heavily involved in training practitioners and researchers. Physicians, social workers, nurses, administrators, mental health workers and staff of long-term care facilities from many colleges, universities and agencies are trained at the Center. Center staff personnel hold teaching appointments at a number of local universities. Federally funded training grants support post-doctoral research and clinical fellows.

COMMUNITY EDUCATION

Speakers Bureau. PGC professionals from the fields of medicine, social work, psychology, research, nutrition and exercise are available at no cost to speak to community organizations and groups of senior citizens, either at their location or at PGC, about topics related to aging.

SERVICES TO INDUSTRY

Services to Industry. Philadelphia Geriatric Center provides training and education to Human Resources and Employee Assistance personnel concerning issues related to family caregiving responsibilities and provides information about available community resources. Programs are also being developed to provide information and case management services to employees.

Mr. BORSKI. Mr. Williams.

STATEMENT OF RODNEY D. WILLIAMS

Mr. WILLIAMS. Because of the lateness of the hour, I also will be skipping over sections of my testimony but ask that the entire document be entered in the record.

Mr. BORSKI. Your entire statement will be included.

Mr. BORSKI. My name is Rodney D. Williams, and I am Executive Director of the Philadelphia Corporation on Aging, the Area Agency on Aging for Philadelphia.

The largest of 52 area agencies on aging in Pennsylvania, the Philadelphia Corporation on Aging, or PCA, is a private nonprofit corporation working to improve the quality of life for older Philadelphians and to assist them in achieving their maximum level of health, independence and productivity. Through a contract with the Pennsylvania Department of Aging, PCA administers Federal and State funds to plan for and coordinate a comprehensive and accessible system of direct services for older Philadelphians.

Philadelphia has received a preview of the upcoming demographic revolution in aging. We rank fourth in the Nation in the number of persons over age 60 and second with respect to the percentage of total population over age 60. More than 1 in 5 residents of our city is over 60, a ratio that the country as a whole is expected to reach only by the year 2010.

Even while Philadelphia is experiencing a decrease in overall numbers, the older segment is increasing in numbers. It is increasing most markedly as a proportion of the total population, and it now accounts for about 21 percent of all residents.

The elder subgroup made up of those 85 and over, the "oldest old," is the fastest, I repeat, the fastest growing segment in the Nation today. In Philadelphia, this group will almost double between 1980 and 1993, making up 10 percent of those over age 60 in the city of Philadelphia.

¹ Last year PCA, under our In-Home Care Program, provided case management services for 8,800 persons and homemaker services for 4,500 persons. Four hundred and two persons attended day care programs through our system and 3,800 persons received more than 800,000 home-delivered meals. Despite the attention and resources we have dedicated to long-term care services, the need vastly outweighs the help available. The future promises even greater challenges. Presently, we are forced to use a system of prioritization, serving those persons in greatest need first.

As a Nation, however, we are finally beginning to confront the reality that our systems and programs designed to care for the elderly are not keeping pace with the escalating need.

Current State and Federal policies are disjointed and fragmented rather than comprehensive and complementary. They continue to address the need for acute or skilled care, overlooking the need for supportive services over sustained periods of time.

With my remaining time, I would like to discuss specific issues which we consider key in tackling the problem of long-term care. The first issue I would like to bring to your attention concerns the shortage of home care workers, not the quality of their care, but

the shortage of home care workers. The direct providers of long-term care, home health and homemaker agencies and nursing homes, are experiencing critical shortages in personnel.

Personal care workers, such as homemakers and home health aides, are critical members of the long-term care service delivery system, providing necessary custodial care. It is becoming increasingly difficult, however, for community-based homemaker and home health agencies to attract and retain quality personnel. Given low wages and benefits combined with stressful working conditions such as dangerous neighborhoods and substandard housing, it is probably not surprising that there is a shortage of chronic care workers. While workers are becoming more scarce, the demand for them is growing. The Department of Labor projects that home health aide jobs will increase at a rate as to make it among the fastest growing occupations during the next 15 years. By the year 2000, the Department of Labor estimates 110,000 new home health aide jobs will be needed, a growth rate of 80 percent.

In Pennsylvania, we are feeling the impact of these trends as we try to serve the elderly. We recognize that the availability of these workers impacts on nearly every solution to the long-term care problem. Serious attention should be given to this issue.

Caregiver support. A second important issue, in fact, is the support for caregivers. And, we have heard a lot about that in previous testimony. Unpaid providers of long-term care, family caregivers, shoulder the major burden when it comes to this Nation's care of the frail and elderly. These caregivers are faced with one of the most stressful jobs imaginable. They face harsh financial burdens, isolation, and health problems of their own brought on by the care demands. Since 1987, the Philadelphia Corporation for Aging has been engaging in a demonstration program for Pennsylvania's family caregivers, called the Family Caregiver Support Program. This program was initiated by Governor Casey. This is a unique program designed to provide relief to caregivers and to help them in their caregiver role. In the last fiscal year we were able to serve 204 family caregivers through this program, doing such things as providing resource counseling on benefits and entitlements, support groups, technical assistance and limited financial assistance for the purchase of equipment and services designed to ease the burden of caregiving. Legislation is pending to secure the Family Caregiver Support Program as a statewide Program, and we certainly hope it passes.

Long-term care legislation. Several legislative measures designed to address long-term care needs are presently before Congress, most notably, the Long-Term Home Care Act of 1989, H.R. 2263—I am sure you know these bills by heart and better than I do. Also, the Elder Care Long-Term Care Assistance Act, H.R. 3140, and the Medicaid Home and Community Care Options Act of 1989, a part of the Omnibus Budget Reconciliation Act of 1989—H.R. 2924.

Both H.R. 2263 and H.R. 3140 create a long-term home care benefit under Medicare including nursing care, homemaker/home health aide services, respite for family caregivers, personal care services, et cetera. Both employ a financing strategy of eliminating the \$48,000 cap on income exposed to the Medicare payroll tax.

H.R. 1453, the third one, amends Title XIX of the Social Security Act to give States the option of providing quality home and community care to the elderly under their Medicaid programs. It builds on a special waiver program originally enacted in 1981 through which 37 States have applied for waivers to pay for home and community care services to help keep frail senior citizens at home instead of forcing them to enter a nursing home in order to receive assistance. P.C.A. in general supports the thrust of these bills. We acknowledge the valuable components of each but recognize that they represent incremental steps, only incremental steps, in filling the gaps in long-term care. They are not comprehensive solutions. The one flaw they all share, from our perspective, is their failure to account for and build onto a national network of area agencies on aging created by the Older Americans Act.

Area agencies on aging are fulfilling a mandate to develop local comprehensive, coordinated systems, and have over 50 years' experience in addressing some of these problems. In over half of the States in the Nation, they have solid care coordination systems while additional States are in the process of developing such systems. There is no question that care coordination provided by the area agencies on aging, is the oldest, most extensive community-based long-term care system in existence.

We, therefore, would encourage that long-term care initiatives such as those I have mentioned be designed to build on the Older Americans Act structures to avoid senseless duplication. We would be eager to share our successful models in case management and community-based care and urge that lawmakers work in cooperation with administrators of Older Americans Act programs.

The last key issue I would like to talk about is national health care. P.C.A. supports the concept of a national health service or insurance. The basic structure of the American health care system has certainly changed dramatically in the past 20 years and is still evolving. A number of forces have catalyzed this process including technological changes and the emergence of the corporate health care industry. The major catalyst, however, has been the repeated attempts over the past 15 years to curb the Nation's expenditures on health care, costs which have been rising at roughly twice the general inflation rate.

Obviously, there are many technical issues to be addressed in planning for a national health care program. But the time is ripe to start these deliberations and to look to broader solutions.

In closing, I would like to urge that we continue this discussion at a White House Conference on Aging. While such a conference has not been officially announced for 1991, word of it has been circulating for many, many months. We believe that it is important that such a forum take place to examine pressing issues in aging and we hope that it is announced with enough notice to conduct the proper planning needed to ensure a serious, high-quality discourse. Further, it is hoped that a significant portion of that conference be focused on long-term care.

Once again, thank you for the opportunity to share some of our views.

[The prepared statement by Mr. Williams follows:]

PHILADELPHIA CORPORATION FOR AGING
TESTIMONY
ON LONG TERM CARE: THE CRITICAL NEED

Hearing of the U.S. House Select Committee on Aging
Subcommittee on Health and Long Term Care
September 15, 1989
Philadelphia, Pennsylvania

My name is Rodney D. Williams, Executive Director of the Philadelphia Corporation on Aging, the Area Agency on Aging for Philadelphia. We commend the members and staff of the Subcommittee on Health and Long Term Care for conducting a series of hearings on the critical issue of long term care.

The largest of 52 Area Agencies on Aging in Pennsylvania, the Philadelphia Corporation for Aging, or PCA, is a private non profit corporation working to improve the quality of life for older Philadelphians and to assist them in achieving their maximum level of health, independence and productivity. Through a contract with the Pennsylvania Department of Aging, PCA administers federal and state funds to plan for and coordinate a

PCA/2

comprehensive and accessible system of direct services for older Philadelphians.

Serving the elderly since 1973, we are acutely aware of their needs and conditions. We have witnessed a remarkable shift in our client population from a younger, more independent group to an older, frailer one with increasing need for health related services. We know from experience why long term care is the most critical aging policy issues facing the United States today.

Philadelphia has received a preview of the upcoming demographic revolution in aging. We rank fourth in the nation in the number of persons over age 60 and second with respect to the percentage of total population over 60. More than one in five residents of our city is over 60, a ratio that the country as a whole is expected to reach only by the year 2010. Even while Philadelphia is experiencing a decrease in overall population, the older segment is increasing in numbers. It is increasing most markedly as a proportion of the total population, now accounting for 21 percent of our residents.

The elderly subgroup made up of those 85 and over, now called the "oldest old," is the fastest growing segment in the nation today. In Philadelphia this group will almost double from 1980 to 1993, making up 10 percent of those over 60. They

PCA/3

are characterized by a high rate of frailty and poverty -- with growing numbers of elderly at risk of institutionalization.

PCA first entered the arena of community-based long term care in 1977. Now, 12 years later, long term care accounts for roughly 60 percent of our annual budget. Through our long term care program, funded primarily with Pennsylvania Lottery dollars, we coordinate and deliver services for older adults with chronic or continuing physical, medical or social needs. Our goal is to help them stay in the community as long as possible. We contract with agencies to provide long term care services in a number of different community and institutional settings, ranging from an individual's own home to community living arrangements.

Last year (FY 1987-88) under our In-Home Care Program we provided case management services for 8,885 persons and homemaker services for 4,570 persons (this is non-medical custodial and personal care such as bathing and grooming, cleaning, laundry, etc.) Four hundred and two persons attended adult day care programs through our system and 3,829 persons received 800,000 home-delivered meals. We processed 6,971 referrals and completed 5,583 assessments for Medical Assistance or state supplement for nursing home or boarding home placement. Through our Community Care Option program 992 frail elderly were diverted from nursing homes and provided with an

PCA/4

array of support services which enable them to remain within their communities.

Through our Domiciliary Care program, 375 individuals with emotional, mental or physical limitations were situated in personal homes with 24 hour supervision. Some 286 complaints regarding nursing homes and personal care boarding homes were investigated through our Long Term Care Ombudsman Program.

Despite the attention and resources we have dedicated to long term care services for our elderly, the need vastly outweighs the help available. The future promises even greater challenges. Presently, we utilize a system of prioritization, serving those persons in greatest need first; the others must wait for help. A 1985 survey of the elderly conducted by the Philadelphia Health Management Corporation found that some 33,400 persons were in need of in-home service but only 18,861 had acquired them -- revealing a sizable unmet need of 14,564 individuals. We can safely project that these figures have grown substantially this past four years.

As a nation, we are finally beginning to confront the reality that our systems and programs designed to care for the elderly are not keeping pace with the escalating need. Current state and federal policies are disjointed and fragmented rather than comprehensive and complementary. Medicare and Medical Assistance programs created by these policies have been changed

PCA/5

over time to offer fewer time-limited services to a population which is growing both in numbers and in need. They continue to address the need for acute or skilled care, overlooking the need for supportive services over sustained periods of time in order to cope with tasks of every day living.

There are, of course, no easy solutions to the problems we face. With my remaining time, I will discuss the five specific issues we consider key in tackling the long term care question. They are the following: home care worker shortage, caregiver support, long term care insurance, long term care legislation and national health care. The first issue I'd like to bring to your attention concerns the the shortage of home care workers.

HOME CARE WORKER SHORTAGE

The direct providers of long term care -- home health and homemaker agencies and nursing homes -- are experiencing critical shortages in personnel. Personal care workers, such as homemakers and home health aides, are critical members of the long term care service delivery system, providing necessary custodial care. It is becoming increasingly difficult for community based homemaker and home health agencies to attract and retain quality personnel. Given the low wages and benefits combined with stressful working conditions such as dangerous neighborhoods and substandard housing, it is not surprising that chronic care workers change jobs frequently or leave the field

PCA/6

entirely. On average the turnover rate is 60% for "paraprofessionals" who work in home care; 80% to 90% leave within two years.

But while workers are becoming more scarce, the demand for them is growing. The Department of Labor projects that home health aide jobs will increase at such a rate as to make it among the fastest growing occupations during the next 15 years. By the year 2000, DOL estimates 110,000 new home health aide jobs -- a growth rate of 80%.

In Pennsylvania, we are feeling the impact of these trends as we try to serve our elderly. We recognize that the availability of these workers impacts on nearly every solution to the long term care problem.

Serious attention on the part of the private and public sectors must be directed to addressing this issue as it will ultimately be a roadblock to our progress if left unattended. Increasing the minimum wage was one important first step. Another would be to enact legislation requiring employers to provide basic health coverage to all workers and pro-rata benefits to part-time workers.

CAREGIVER SUPPORT

PCA/7

The second important issue I'd like to discuss is that of support for caregivers. Informal, unpaid providers of long term care -- family caregivers -- shoulder a majority of the burden for this nations' care of the frail elderly. Contrary to popular belief, most of the care received by frail elderly is provided not by social service workers and health care professionals but by spouses, daughters, siblings and other family members. Recent national studies show that some 80% of care for dependent older adults is provided by family members.

These caregivers (most of whom are themselves middle aged and elderly) are faced with one of the most stressful jobs imaginable as they provide around-the-clock care for their older loved ones. Often they must also care for children in addition to retaining employment. They face harsh financial burdens, isolation, and health problems brought on by the care demands. These caregivers must be recognized and supported by programs and services we develop so that they may continue providing the essential care needed.

Since 1987, PCA has been a demonstration site for Pennsylvania's Family Caregiver Support Program initiated by Governor Casey. This is a unique program designed to provide relief to caregivers and to help them in their caregiver role. In FY 1988-89 we served 204 family caregivers through this program, providing resource counseling on benefits and entitlements, support groups, technical assistance and limited

PCA/8

financial assistance for the purchase of equipment and services to ease the burden of caregiving. Legislation is pending to secure the Family Caregiver Support Program as a statewide program.

Conversations about long term care which do not acknowledge the family caregiver are deficient -- as would be any comprehensive plan or design which did not set out to provide support to caregivers. Family and medical leave legislation is one creative approach to consider. It would provide job security for employees taking unpaid leave to assume caregiving responsibilities.

LONG TERM CARE INSURANCE

The area of long term care insurance in the next I will address. Private insurance to help finance long term care could fill a great void in available help for those in need of continuing care. In addition, it could also help ease the public's financial burden by shifting some of the costs of care to the private sector.

But our experience with individuals who have purchased long term care insurance policies and our examination of policies now on the market raise serious concerns. Policies available do not address the real needs and circumstances of most aging people. While they are improving, they are structured along similar

PCA/9

lines to Medicare; they help those with acute medical conditions who are in need of short term care while ignoring those in need of long term care. We need legislation to safeguard against abuse in long term care insurance and to assure quality policies. The industry is growing so rapidly that now is the time to establish standards to avoid the kind of abuses that lead congress to regulate Medigap insurance.

To date, only 26 states have enacted protective legislation in this area; we have more than one bill pending in Pennsylvania. National legislation could speed up the progress in this direction. We urge careful consideration of HR 1325, introduced by Congressman Stark. It establishes minimum standards for policies, building on the model state statute developed by the National Association of Insurance Commissioners. While the NAIC standards are not as high as we would like, there is indication that they are evolving to be more consumer directed.

LONG TERM CARE LEGISLATION

Briefly now, I'd like to discuss national legislation on long term care. Several legislative measures designed to address long term care needs are presently before Congress -- most notably the Long Term Home Care Act of 1989 (H.R. 2263), the Elder Care Long Term Care Assistance Act (H.R. 3140) and the

PCA/10

Medicaid Home and Community Care Options Act of 1989 (part of the Omnibus Budget Reconciliation Act of 1989, H.R. 2924).

Both H.R. 2263 and H.R. 3140 create a long term home care benefit under Medicare including nursing care, homemaker/home health aide services, respite for family caregivers, personal care services, etc. Both employ a financing strategy of eliminating the \$48,000 cap on income exposed to the Medicare payroll tax.

H.R. 1453 amends title XIX of the Social Security Act to give states the option of providing quality home and community care to the elderly under their Medicaid programs. It builds on a special waiver program originally enacted in 1981 through which 37 states have applied for waivers to pay for home and community care services to help keep frail senior citizens at home instead of forcing them to enter a nursing home in order to receive assistance.

PCA supports the general thrust of these bills. We acknowledge the valuable components of each but recognize that they represent incremental steps forward in filling the gaps in long term care not a comprehensive solution. The one flaw they all share, from our perspective, is their failure to account for and build onto the network of Area Agencies on Aging created by the Older Americans Act.

PCA/11

Area Agencies on Aging, fulfilling our mandate to develop local comprehensive, coordinated systems of home support services, have fifteen years experience in addressing the very problems policy makers are currently wrestling with in attempting to devise a workable long term care program. In over half the states in the nation we have solid care coordination systems while additional states are in the process of developing them. There is no question that our care coordination system is the oldest, most extensive community-based long term care coordinating structure existing in the nation. Why start from scratch in conceptualizing a broader provision of care?

We therefore encourage that long term care initiatives such as these be designed to build from the Older Americans Act structures to avoid senseless duplication. We are eager to share our successful models in case management and community based care and urge that lawmakers work in cooperation with administrators of Older American's Act programs when designing this type of legislation.

NATIONAL HEALTH CARE

Another area I want to touch on here is that of national health care. PCA supports the concept of a national health service or insurance. The basic structure of the American health-care system has changed dramatically in the past 20 years and is still evolving. A number of forces have catalyzed this

PCA/12

process including technological changes and the emergence of the corporate health care industry. The major catalyst, however, has been the repeated attempts over the past fifteen years to curb the nation's expenditures on health care, costs which have been rising at more than twice the general inflation rate.

This country now holds the distinction as the only industrialized country, other than South Africa, that does not have a national health program which provides everyone with the basic necessities of health care. Thirty seven million Americans are without insurance. The sick are turned away from hospital emergency rooms and doctors' offices because they either lack insurance or have the wrong kind.

Obviously, there are many technical issues to be addressed in planning for a national health care program -- the organization of care, the development of new models of primary care, the problems of equitable financing, the huge problem of costs -- but the time is ripe to start these deliberations and look to a broader solution.

CONCLUSION

In closing, I'd like to urge that we continue this discussion at a White House Conference on Aging. While such a conference has not been officially announced for 1991, word of it has been circulating for several months. We believe it is

PCA/13

important that such a forum take place to examine pressing issues in aging and hope that it is announced with enough notice to conduct the proper planning needed to ensure a serious, high quality discourse. Furthermore, it is hoped that a significant portion of the conference be focused on long term care.

Thank you again for this opportunity to share with you our views on long term care.

Mr. WILLIAMS. A written statement by Linda M. Rhodes, Secretary, Department of Aging, Commonwealth of Pennsylvania, is hereby submitted for the record. She unable to attend this hearing.

Mr. BORSKI. The statement of Linda Rhodes will appear in the hearing record at this point.

[Statement of Ms. Rhodes follows:]

Statement by Linda M. Rhodes
Secretary, Pennsylvania Department of Aging
September 15, 1989

Good morning. My name is Linda M. Rhodes and I am Secretary of Aging for the Commonwealth of Pennsylvania. I am here today to speak on the issue of long term care and Pennsylvania's response to the expanding long term care needs of our growing population of older people.

Long term care is probably one of the most confounding problems with which our society is wrestling right now. Confounding, because there are no easy answers, no cheap solutions and no quick fixes.

Confounding, because, as Congress recently discovered, as soon as you think you have plugged the leak at one end of the long term care pipeline, more leaks spring up elsewhere along the system. And, confounding because it's an issue that has no enemies, but few friends.

Over the years I've discovered that there are three myths that permeate the issue of long term care. The first myth is that long term care is only nursing home care. Those of us who have spent a great deal of time in the long term care field know that it encompasses much more than institutional-based care.

In reality, less than 5 percent of older people reside in nursing homes--the remainder live in their own homes or with family. It is there, within their own homes, that most of the people need most of the services we now call long term care; services such as in-home care, attendant care, home delivered meals, chore services, and more. And it is in the community where we can most effectively and efficiently deliver these needed services.

The second myth of long term care is that Medicare will pay for it. Older people who for years have counted on Medicare to pay their hospital bills, are surprised and devastated to learn that Medicare pays less than 2 percent of all nursing home care and almost nothing for home-based care.

Half of all long term care nursing home services are paid for out-of-pocket by individuals and families and nearly half is government-funded through the Medicaid program. At present, most private long term care insurance policies are too expensive and too limited in scope to benefit those who need it most.

The third myth of long term care is that it won't affect me. The fact is that most Americans sooner or later will come in touch with long term care, either through their own needs or those of a parent, grandparent or spouse.

In Pennsylvania we have particular cause for concern for two key reasons. First, we are a major greying state with over 2.4 million people over age 60. At present, we rank second to Florida in the proportion of our older population to the rest of the population. And we rank fourth in terms of pure numbers of older people. Most significantly is that our over-85 population--the heaviest users of long term care services--has increased by more than 60 percent in this decade.

Our second reason for concern has to do with the way in which we fund long term care services in Pennsylvania. With the birth of the Pennsylvania Lottery in 1972, the decision was made to fund aging services through lottery proceeds. To our knowledge, Pennsylvania is the only state that devotes net Lottery profits to services for older people.

The good news is that over the years the lottery has funded more than \$4 billion in services for older people. The bad news is that the cost of these services will exceed available lottery fund dollars for the first time in the Lottery's history in the 1990-91 fiscal year.

Coupled with this is the fact that the federal share of aging services resources has declined steadily since 1985, placing an even greater burden on our state's resources.

Although we remain optimistic that current aging programs will continue to be funded, our concern is that the shortfall will prevent new programs from being initiated and new persons from being served. As a preventive measure, Governor Casey has begun to put back some Aging programs into the General Fund to free up more lottery fund dollars. But the need is great and it's growing.

Allow me now to address some of the ways in which we are beginning to address these needs.

Preadmission Assessment - Many of you have become familiar with the term preadmission assessment through the recent OBRA legislation. OBRA now requires all states to assess individuals applying for nursing home care for mental health, mental retardation or related disorders with the goal of assuring appropriate treatment of these individuals. In Pennsylvania, we've been assessing people before they enter the nursing home for the past four years as part of what we call our LAMP program (Long Term Care Management and Assessment Program).

The goal of the LAMP program is to arrange for the most appropriate level of care for Medicaid-eligible nursing home applicants. The LAMP program began as a pilot project in seven Area Agencies on Aging and we have plans to expand to include an additional 23 sites.

What this means for the older person is that we have the ability in these areas to offer intensive in-home services as an alternative to nursing home care. These services cannot cost more

than 45 percent of the cost of the nursing home care. We have found that, on the average, where nursing home care cost \$60 per day, we can provide in-home services to that person for about \$23 per day.

In the 1987-88 fiscal year, we assessed 13,000 people. Of those, 23 percent had been referred to a higher level of care than was actually needed. Because of the community-based services we were able to provide, 14 percent were able to stay in their own homes or with family. For this, the Commonwealth spent a total of \$10 million service dollars, as opposed to the \$63 million in state and federal dollars that would have been spent on nursing home care.

Managed Care - The key to the Intensive In-Home Services program is managed care. Managed care means that we help the older person or family identify and tap the community-based services they need to maintain a quality of life within the home. Perhaps they need an adult day care center or respite care, homemaker services or personal care assistance. Most families don't even know what services are out there or which ones they are eligible for. With managed care, we are able put together the pieces of the puzzle for that family and help them tap the resources to pay for many of these services.

Family Caregiver Support Program - The Family Caregiver Support Program is one we are most proud of. It places the emphasis on the families who are providing support to older relatives in the home.

A national survey on caregiving conducted by the American Association of Retired Persons showed that four out of five older people with physical or mental impairments are able to avoid institutionalization because of assistance provided by family members or friends. It is estimated that there may be as many as 7 million caregiving households in the United States, providing an average of 12 hours of care each week.

The Family Caregiver Support Program offers financial help, benefits advice and some hard services to ease the stress associated with caregiving. In some cases, we've been able to add wheelchair ramps, stair climbs and other home modifications to help make the older person more independent of the caregiver. One case in particular I remember is an older man who, in addition to multiple health problems, was an amputee. He felt a motorized wheelchair would help him regain some of this independence. Through the help of the Family Caregiver Support program, he was able to obtain that wheelchair.

The Family Caregiver Support program is currently a demonstration project in four sites and will be expanded to eight in the near future.

Transitional Care - The Transitional Care program is another demonstration project aimed at preventing premature institutionalization of older people. Transitional Care focuses

on older people who are being discharged from an acute care setting to the home. What we do is work with hospital discharge planners to identify those older people who will need intensive in-home services immediately following their hospital stay and provide those services on a short-term basis. The goal of the transitional care program is to aid the person's convalescence to prevent re-hospitalization or nursing home admission.

Most of the older people who have benefited from transitional care are those who live alone or whose spouses or families are unable to provide the care they need. An initial evaluation of the program has demonstrated that the program has been successful in providing the needed services to reduce the functional dependency of the patient on the caregiver and in preventing re-hospitalization or premature institutionalization.

Cost-sharing - In addition to the direct benefits provided by both the Family Caregiver and Transitional Care programs, another significant factor is that we have introduced cost-sharing into these programs.

Cost-sharing is a new concept in aging programs and heretofore untried because of prohibitions in the Older Americans Act. Currently, older people with poverty level incomes are given priority for services. But often, as I travel across the state, I hear from older people and their families that, while they cannot afford to pay the full cost of the service, they would be willing to pay a share of that cost. Maybe they can't afford \$15 a day for adult day care, but they could pay \$10.

I firmly believe that cost-sharing is the wave of the future and a legitimate way to expand services to more people without draining service dollars. Pennsylvania is being observed by other states as well as the Administration on Aging to see if cost-sharing is indeed a viable option for aging services.

Long Term Care Council - The Commonwealth of Pennsylvania is spending nearly \$1 billion dollars annually for various aging services. These services are offered through a number of state agencies without any coordination or strategic planning. The result is a fragmented service delivery system with overlaps and gaps.

In an effort to improve this system as well as to assure that adequate and appropriate long term care services are accessible and available to those in need of them, Governor Casey in 1988 established the Commonwealth's first Intra-Governmental Council on Long Term Care. The Council is now the vehicle through which planning and policy development for long term care is conducted.

I am privileged to chair this council and to have on it other members of the Governor's Cabinet, several legislators, representatives of the long term care industry, the business and labor communities and consumers.

Over the past months, the Council and its committees have been working diligently for long term care reform in the Commonwealth. We began by looking at the current system--who was doing what and did it make sense or was there a better way. We divided the long term care system into three key areas: systems development, access and supply and finance. In simple terms: what is needed, how much is needed and how do we pay for it?

The Council is currently preparing a comprehensive report which will provide a series of options for reshaping the face of long term care in Pennsylvania. Although that report will not be ready until later next month, I would like to share with you some preliminary recommendations.

- 1) That a balanced continuum of in-home/community-based services and facility-based long term care services will best meet the needs of the population.
- 2) That the needs of the 18 and over functionally disabled population will serve as principle eligibility criteria for the delivery of long term care services.
- 3) That access to the long term care delivery system will be through a single point on entry and that services be maintained through a coordinated system of care management.
- 4) That the continuum of long term care services will be adequately financed through the encouragement of private sector initiatives and through maximizing public dollars through cost-sharing and other initiatives.

I sincerely believe and hope that you would agree that Pennsylvania is doing its part in attempting to respond to the complex issue of long term care. But it's a balancing act at best and smoke and mirrors at worst. We are reaching our limit in terms of what we can do with the precious little resources we have left.

If there's one plea I make to you this morning, it is that the federal government work in partnership with states in developing a long term care policy. We cannot continue to plug the holes that the federal government leaves when it decreases its share of the long term care bill. We need clear policy jointly engineered by federal and state policymakers that addresses the needs of a more frail, older population; that recognizes and rewards the contributions of family caregivers; that acknowledges the home as the preferred place of care and focuses resources on in-home services; that protects older people and their families from the crushing costs of long term care.

Thank you.

Mr. BORSKI. Well, thank you very much, Mr. Williams, Mr. Po-dietz, Ms. Stagg and Ms. Hahn. I want to ask you a couple of general questions, and I think first I will ask specific questions of Ms. Stagg, if I may. Do you have any dollar figures as to the amount of money that it costs to get long-term care insurance for let's say, a 50-year-old, a 60, or 70-year-old person? Can you give a number that goes with that?

Ms. STAGG. I could give you a number off the top of my head, some general ranges. I don't have anything in front of me. The annual premiums for these policies do vary widely depending on all kinds of things because that would have to do with how much coverage you bought, how much of a dollar-per-day benefit you wanted, all of those things as well as what age you are. Let's say for the same policy, 4 years of coverage, \$100 a day, covers several things. It would range something like this: at age 55 a policy might cost somewhere from \$300 to \$500, \$600 a year. At age 65 a policy might cost as much as \$1,000 a year. At age 75 that same policy would probably cost \$1,500 to \$2,000 a year.

Mr. BORSKI. Tell me what that would cover?

Ms. STAGG. Well again, I am just sort of making it up off the top of my head—a typical policy on the market today would offer people choices. It might offer them say a coverage of \$80 a day for nursing home care, for 3 or 4 years. It might have a home health care benefit that would pay 50 percent of the nursing home daily amount. If you got care in the home, it would pay \$40 a day. That care might be skilled nursing or include some help from home health aides or others, depending on what the policy said. The policy might restrict that care to a prior stay at a hospital or prior stay in a nursing home, which is a restriction that many people don't like and which definitely reduces the likelihood of your getting the home care benefits.

The policy might include options such as an inflation option but would cost more. I would say to anyone looking at a policy, look at several, ask to read the contract itself, get a buyer's guide and really compare in columns the benefits you are getting and the premiums you are paying, and take your time. Be very careful. The policies are not for everyone.

Mr. BORSKI. Right. I think you made that point very well during your testimony. I take it it stands to reason that the younger you are the cheaper the policy would be. Someone 20 years of age may be paying \$100 a year, \$150 a year?

Ms. STAGG. Although I think very few policies are bought by people that young at this point, the rates would be very low. The point I want to make is, I think we have to think of long-term care, the financing picture, in two different ways. There are immediate needs and you heard many of those today. But, for much of the population, what they may need is when they retire and when they are older. They could pre-fund it over time. They could buy these policies or something that is similar to that which may evolve. And, for the long-range policy for the next generation, this might be a very good way to help on the cost of that.

Mr. BORSKI. I just have an idea or two I would like to share with you, if I may. I am just curious if something is being studied or perhaps could be looked at by your group. One would be a possibility

of a home equity transfer. Assume that the elderly have a nice asset, is it possible to transfer the equity in that home to a single premium payment that would perhaps cover long-term care?

Ms. STAGG. That is really an interesting idea. I had not quite included it in my testimony but, as you mentioned, there are a number of options people are looking at and using today to pay for home care. Similar to what you have mentioned is the fact that they would sell their home and buy another home and long-term care in a life care community. I think that long-term care insurance as I describe it will provide another alternative because it assumes that a person is going to go on living in their home or some place of residence and this only covers the long-term care costs that they would occur in their home or later in a nursing home. So, they are really two different things. And, a home equity conversion is another thing where you just start drawing down the value of your home to pay your expenses, but a lot of people have been hesitant to do that.

Mr. BORSKI. Yes. The thought occurred to me that if you retire, let's say at age 65, and it could be projected for the next 20 years or however long your actuaries would go, perhaps a one-time premium could be considered.

Ms. STAGG. I think a single premium payment policy might be a possibility. We could assume that people could somehow save the money or there might be some other kind of savings mechanism, and when they reached 65 they'd take that money and buy a policy. I don't know of such a program existing today, but it's an interesting idea.

Mr. BORSKI. And my idea, again, is that the equity that a person has developed throughout his life is likely to be in place and, in my view, would be something that could be used. I was also curious about an idea that came to mind which is the conversion of life insurance. You need more life insurance as you are younger and the older you get you might not need as much and the policy could conceivably be converted at that point.

Ms. STAGG. In fact, I also just mentioned, but didn't describe in detail, products that have just come onto the market in the last 2 or 3 years that are obviously sold to relatively young people, usually under the age of 55. There are life insurance products in which you have life insurance but you also have some long-term care coverage as part of the life insurance policy. They are what are called "accelerated benefit policies," or a better way to look at it would be as a convertible policy—it can change from life insurance to long-term care if you need it. If you don't use it for the long-term care, you still have the life insurance.

Mr. BORSKI. Could each of you perhaps respond to the question that I had earlier. Are people just not aware that they would not be covered should they need to get long-term care?

Ms. HAHN. Yes. As somebody who works directly with clients, I have to tell you that they are not aware. People just do not understand what Medicare provides, they do not understand what Blue Cross/Blue Shield policies provide, they do not understand. Poor people who are on Medicaid, have it best because Medicaid pays for a while for medical services. They just cannot believe that the kinds of custodial care that they need as they get older will not be

covered by any of those three funding sources that I just mentioned.

Let me just say one thing, in terms of custodial care. People with Alzheimer's disease or other dementia-related diseases actually don't very often have a lot of physical problems. So they may not need long hospital care. Unfortunately, most of these private insurance products that you are talking about where Medicare doesn't kick in, they don't provide what people really need, the nonmedical custodial care. And, they are very surprised to find that none of their policies cover it. I have to tell you that as I became more involved in geriatric social work, it was news to me. It was absolutely news to me that these kinds of things were not provided by the kind of insurance these people had. I don't think that most Americans know and they aren't worried.

Mr. PODIETZ. I'd like to say that HHS sends this Medicare booklet out. I suspect that there aren't very many elderly people that can work their way through it. It is a great resource but it requires somebody to communicate it to them, to explain it to them.

Mr. Williams talked about the case management program of the Philadelphia Geriatric Center. We have one of those sites through PCA, and we have five staff members that work in a 2-mile radius of the Center and we spend full-time effort explaining to people their benefits. A colleague of ours in an adjacent hospital in the Albert Einstein Medical Center has a program where they spend three full-time equivalent man years of work trying to sort out the elderly health insurance claims because they literally come in with bags and bags of claims. They don't know how to understand them. There are many people who have multi-Medigap policies despite the fact that they are not supposed to be sold like that.

So there is a tremendous amount of confusion. There is a tremendous amount of lost dollars that go to insurance providers that are not really serving the best needs of the consumers while other carriers are trying to do a very responsible job of figuring out appropriate ways to insure risks. So there is much more that needs to be done to help the elderly understand what they are entitled to and to help them get it.

Mr. BORSKI. Mr. Williams?

Mr. WILLIAMS. It certainly goes without saying that many people are surprised in terms of the lack of coverage that is available in this country until they need a particular service or benefit. I think that is changing somewhat. And, I cite two examples.

I am not exactly sure, but there was a study done about 6 or 9 months ago. What they did, they asked people of all age groups if they would be willing to pay more money, more taxes—they didn't define, "more," so until you get the bill, you were never sure—but in general, these groups of all ages agreed that they would be willing to pay more taxes if, in fact, their loved ones, their spouses, themselves, whomever would be covered with respect to long-term care. Now, long-term care to them, I think in their minds, primarily meant nursing home care. I am not sure they grappled with institutional versus community-based care. But, in terms of the overall notation, "is it worth something?" they say, yes.

Secondly, the big problem with the catastrophic health insurance bill, at least from many people's perspective, is not the cost but the

coverage. Had the bill included some even beginning component of long-term care, a lot of people would have paid and paid more. So, I think that overall people are beginning to understand that the coverage is not there, which could really devastate a family both financially and emotionally, and something has to be done about it.

Mr. BORSKI. Yes. I believe that people are not aware. I believe that people would pay more to insure themselves to have long-term care benefits and I think that is what you are—

Mr. WILLIAMS. But, that is not in this bill. Congress didn't go far enough.

Mr. BORSKI. In the catastrophic bill.

Mr. WILLIAMS. In the catastrophic bill.

Mr. BORSKI. There is no question about that. My question, though, is the average American citizen not aware of or doesn't understand that should they need more care, they don't have it. I believe they think they have it.

Ms. HAHN. That is right. Ask you parents if they think they have it.

Mr. BORSKI. Well, ask your peers, your neighbors. Ask Mr. Gibbons here today. Any working person assumes that if they have a good medical policy that they are covered for these. They are not. I think that is the biggest problem. I agree, very much, sir, that if you asked people would they pay more taxes for long-term care should a need arise, they would say, yes. I don't think people understand that they are not covered; some, of course, do know.

The other question that I do want to ask each of you, and I think you brought it up, Mr. Williams and Mr. Podietz, earlier is, the catastrophic bill itself, which we could spend 2 days trying to find out what's going to happen or what's happened or what should have happened. But the interesting point to me is, if there is a national solution to long-term care, and, if part of that solution is to increase taxes, would the elderly be willing to have their taxes increased along with everyone else.

If there were a way to draw up a bill that you would receive money from all Americans, young and old, or all working Americans, I should say, not 9-year-old people for instance, but it included retirees who pay taxes. Does anyone want to take a shot at that?

Ms. STAGG. I really think that yes, people would be willing possibly to pay more—they expect to pay both publicly and privately. The real challenge is how can you project what the cost will be and what the benefits will be so that you could give them an honest picture of what they would be paying for more than just a year at a time. If they know what it is, then many people would be willing to pay more.

Ms. HAHN. I think that one of the problems that we have is in separating the generations, and that we get really tight interest groups. Obviously, the elderly as many other groups, now have advocating status. So many of us wanted to help the elderly that in some ways we neglected our children, and we have this generational split. I think the elderly would more likely be more willing to pay increased taxes if they felt that the burden was shared. That is the problem with the catastrophic health bill—they thought that it was shared across the board.

Somehow we need to begin to, I think, legislate tax reform in public programming and public policy, perhaps something that is more broad-based. As I said, I am not a tax expert but I think, from the elderly that I know, they felt that the coverage was really what they needed and that the cost would be shared by the majority of working Americans. My feeling is that people are getting more and more scared, that they know it is going to cost and that it has to come from somewhere. My clients are really scared that that is going to happen to them, and I think that they would be willing.

Mr. WILLIAMS. I guess I second that. I think that one of the problems with the catastrophic health insurance bill as a public policy option was the fact that maybe for the very first time it spread the risk of the cost only among those persons who would benefit. If the cost had been spread across the general population, it would have been less. Everybody would have paid, and I think that is what people have come to expect—that if you share, in fact, the cost through all age groups, if that were to occur, and to the extent that legislatures in the future introduced, I believe, covering long-term care type benefits, a shared cost across all the population would be acceptable and I would imagine that older people would be more than willing to pay their fair share of the costs. But, they should not be asked to pay the total cost of the program.

Mr. BORSKI. I would just say that the intent of the catastrophic bill was good. If it turns out that people don't want it and I think that part of the reason is that in a lot of instances the people who you are asking to pay have already paid in the private sector for coverage and any governmental coverage will be duplicative. Now, it is clear that at this point there is not a whole lot of long-term care insurance available, but if you think that this will only be funded by the working population, I believe that is a huge mistake and will never get legislation passed without the elderly paying something. I am just curious if part of the reaction to the catastrophic bill is if they should pay at all.

Mr. PODIETZ. I think the elderly, like all of us, want to pay their fair share. None of us wants a free ride. They just want an understanding of what it is that they are about to get, what the potential is, meaning the service, and relating that risk to the cost that they are going to have to pay for.

Mr. BORSKI. Let me thank you again all for coming by and giving your expert testimony. It was very much appreciated. I would ask, if you don't mind, if after we go over your statements a little more, that perhaps we may write to you and ask for further interest to some of your testimony.

[Whereupon at 12:25 p.m. the hearing was adjourned.]

APPENDIX

September 25, 1989

Congressman Robert Borski
314 Cannon Building
Washington, D.C. 20515

ATTENTION: Mary McSorley, Legislative Liaison

The Philadelphia Mental Health Aging Advocacy Committee a coalition composed of administrators, practitioners and consumers committed to the cause of quality long term care for the elderly appreciates this opportunity to express our concerns regarding the needs of a population which has been undeserved and overlooked. Federal policy in recent years has been to accelerate the deinstitutionalization of the mentally ill from State mental hospitals. Many of the mentally ill have been transferred to nursing facilities or boarding homes. While Federal policy has encouraged the reduction of state hospital populations, existing reimbursement mechanisms have restricted the provision of adequate services for persons requiring long term mental health care.

Medicare, for example will not reimburse for psychiatric services provided to residents of nursing facilities. State medicaid plans, developed in accordance with guidelines established by the Health Care Financing Administration (HCFA) do not meet the costs of mental health services in nursing homes. As you know the passage of the Nursing Home Reform Legislation and the Omnibus Budget Reconciliation Act of 1987, (OBRA) has served to discourage the placement of individuals with long standing psychiatric problems in nursing homes unless they have major physical problems. For those who are in boarding homes or living in their own homes the prospects for appropriate care is questionable due to the limited medicare and medicaid reimbursements.

For the population with long term mental health problems who may also have physical problems, the expectation that they can independently seek help from a community mental health center is not realistic. This group requires outreach, case management, and in-home care which is more costly then the on-site services available from a community mental health center. Clearly, there is a critical need for review of existing Federal/State funding mechanisms to effectively deal with the deinstitutionalized population as well as those with long standing psychiatric disorders who have been living in the community.

Federal policy rationale for the lack of reimbursement is that the care of the mentally ill has been and still is a State responsibility. Current policy and practices have resulted in significant numbers of the mentally ill being trapped in a cycle of hopeless chronicity. While people of all ages are affected by the existing service gaps, the impact on people 60 years of age or older is particularly striking. The relationship of poverty and physical illness characteristic of this cohort to mental illness has been consistently documented in the professional literature.

In addition to their physical problems, the elderly are more likely to have life situations such as reduced income, loss of social roles, stigma of ageism, loss of relatives or friends all of which impact on their psychological well being. It is estimated that 18 to 25% of the elderly experience mental health problems ranging from mild depression to acute psychosis. Many people with long standing disorders may not be cured but with assistance can be maintained with a greater degree of dignity than has been demonstrated in the past.

We commend you and your staff for the interest you have shown in developing a Federal long term care policy. Mental health is so inextricably linked to physical well being that it should be considered as an essential element of extended programs for people of all ages. If in the course of your committee work, additional information concerning long term mental health care is needed, we would be glad to respond to your requests.

Sincerely,

Trudy Persky

Trudy Persky, Facilitator
Philadelphia Mental Health Aging
Advocacy Committee
520 N. Delaware, 4th Floor
Philadelphia, PA. 19123
Telephone: 215-923-0400